VOICE OF THE DIABETIC

A SUPPORT AND INFORMATION NETWORK

The Diabetics Division of The National Federation of the Blind

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Voice of the Diabetic is a national publication of the Diabetics Division of the National Federation of the Blind. It is read by those interested in all aspects of blindness and diabetes. We show diabetics that they have options regardless of the ramifications they may have had. We have a positive philosophy and know that positive attitudes are contagious!

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Board members of the Diabetics Division of the National Federation of the Blind. All are early-onset, insulin dependent diabetics who had diabetes for many years (25½ to 55½ years). Four have had a transplanted kidney for 3½ to 11 years. They all agree that although diabetes is a nuisance and an inconvenience, it can also be a motivating force. Back row, left to right: Karen Mayry, president; Ed Bryant, vice president. Front row, left to right; Dolores Olson, secretary; Carol Anderson, treasurer; Betty Walker, vice-president.

Thank You!

The Diabetics Division of the National Federation of the Blind says THANK YOU to Sandoz Parmaceuticals. Sandoz is providing the funds to cover the cost of this issue of *Voice of the Diabetic* which will specifically cover transplantation. Sandoz is a large pharmaceutical company that produces Sandimmune (cyclosporine), which is a leading immunosuppressive drug used in organ transplantation.

We realize that Sandoz Pharmaceuticals produces their product and of course promotes it, which is natural. You should know that Sandoz, however, has placed no special requirements regarding this issue of our newsletter. It is published by the Diabetics Division of the National Federation of the Blind and everything it contains has been selected by us. We stress this point only because we think it's important that our readers know that *Voice of the Diabetic* is written for the purpose of our members and to educate the public.

Since Sandoz Pharmaceuticals is providing us with outside financial assistance, this issue's circulation will be well over 30,000. Also, since our special emphasis is on diabetes, we hope to enlighten diabetics about renal failure and prove the importance of at least considering a kidney transplant.

Our publication covers all areas of diabetes, but this issue deals with the one ramification that is probably, as far as health goes, more important than any other. It is vital that we, as diabetics, know that there is more than one option if our kidneys do fail.

Again, the Diabetics Division of the National Federation of the Blind says THANK YOU to Sandoz Pharmaceuticals for financing this issue of *Voice of the Diabetic*.

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The Promise of Cyclosporine

(Editor's Note: The following has been condensed from "The Promise of Cyclosporine," an article by David L. Winter, M.D., Director of Medical Research for Sandoz Pharmaceuticals. Reprinted with permission of the author.)

What Is Cyclosporine?

Cyclosporine, a powerful, selective suppressor of the body's immune response system, has transformed the field of organ transplant surgery. Like another revolutionary drug, penicillin, cyclosporine was discovered quite by accident when a vacationing scientist from Sandoz Limited in Switzerland gathered some soil samples from a Norwegian fjord for company use.

Microbiologists at Sandoz found a new strain of fungi imperfecti. One of the samples that they discovered contained a material which was active in killing other types of fungi. Although the discovery was interesting, the material was not considered to be of any medical importance and was not actively explored.

In 1972 Jean Borel, a Sandoz biologist, reexamined the material and found that there was some medical significance in it. She noticed the chemical properties of the material had an effect on the immune system which suppressed it.

By 1974, the chemical compound had been termed cyclosporine and had been shown to be an effective immunosuppressant. Most important was the discovery that the drug was not toxic to bone marrow or cells in the body; when cyclosporine is no longer administered, the white blood cells which it suppresses resume their bodily functions.

Investigators began long-term studies and experiments with the drug on animals in 1976. The first studies on humans were conducted in England and the success there brought the drug to American transplant centers. In 1983, the drug was approved by the U.S. Food and Drug Administration for general use in kidney, liver and heart transplantation. The trade name for the drug is Sandimmune.

What Does the Drug Do?

When a transplant is performed, a doctor places a donor organ into the patient. The organ is foreign to the patient's body and when it is placed there it evokes a complex immune response. White blood cells are activated to kill the foreign invader. Most interesting is the complex procedure which leads to this rejection of a foreign object. There are many types of white blood cells and they all have a different function in this process.

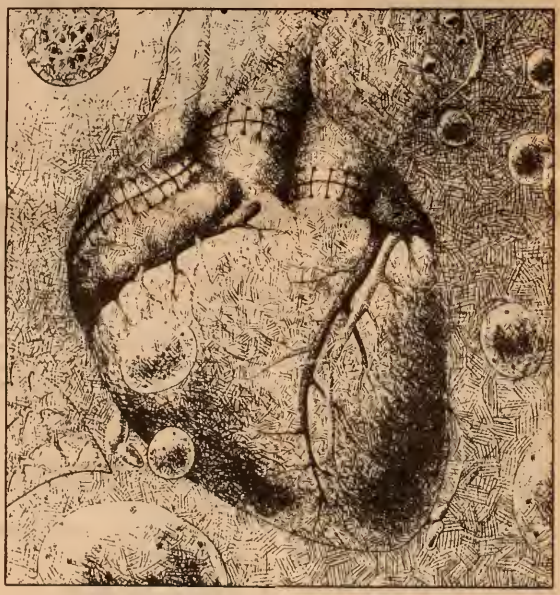
Lymphocytes are the cells which locate the foreign object and ensure that only the object is attacked. Without these cells our entire body might be rejected in an immune response.

Macrophages,polymorphonuclearleukocytes and monocytes are the cells which initiate an attack on the invader and control the intensity.

While the white blood cells are attacking the intruder, they produce chemicals called antibodies. Through the cooperation of these antibodies and the other white blood cells, the immune response is complete.

Rejection of a transplanted organ can be severe or it can never happen at all. This can be affected by two factors: if the organ being transplanted is genetically similar to the body it is being placed in (i.e. the organ is from a close relative or it is tissue that has been removed from the patient and then replaced), then there is less or even no chance of rejection. The second factor depends upon the immune response level of the patient.

Cyclosporine is important because



it lowers the immune response level of the patient by suppressing the white blood cells. As mentioned earlier, the added importance of the drug is that the white blood cells start working again to protect the patient from other "intruders" once cyclosporine is no longer administered.

How Much Has the Drug Improved Survival Rates?

Controlled studies of kidney transplant patients were conducted at major institutions in the U.S., Canada and Europe between 1978 and 1982. Patients were chosen at random to receive either cyclosporine or azathioprine, a conventional immunosuppressant. The results from all trials were quite consistent: the transplanted kidneys of patients receiving cyclosporine survived significantly longer. In addition, the patients experienced fewer rejection episodes, fewer infectious complications and shorter hospital stays. In combined averages from five studies of patients on cyclosporine and azathioprine, those on cyclosporine had a one-year transplant survival rate of 80 percent compared with 61 percent for those on azathioprine. All transplants used kidneys from cadavers.

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Advances in Kidney Transplantation of Special Interest to Patients with Diabetes

by Nicholas J. Feduska, M.D.
Professor of Surgery,
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Dr. Nicholas J. Feduska is Professor of Surgery and a kidney transplant surgeon at the University of California-San Francisco. He and his colleagues have performed more than 3,000 kidney transplants, which represents the largest experience of any single transplant team in the world. This article will be of special interest to patients with diabetes, as it discusses recent advances in kidney transplantation and presents the most current data relating to the success rates for such transplants.

In the United States today, the lives of approximately 110,000 patients with kidney failure are being sustained with chronic hemodialysis (use of the artificial kidney machine) or peritoneal dialysis (a type of dialysis that involves the introduction of fluid through a catheter into the abdominal cavity). It is estimated that 20-25% of these patients have kidney failure associated with type I diabetes mellitus ("juvenile-onset diabetes," "brittle diabetes," "insulin-dependent diabetes"). Some of these diabetic patients are in the process of being prepared for related donor kidney transplants, while approximately 2,500 are on waiting lists for cadaveric transplants.

Data from the Health Care Finance Administration indicates that more than 8,000 kidney transplants were performed in 1986 alone, and that the number of kidney transplants performed in recent years has been increasing. Rather consistently, between 60-70% of the transplants have come from cadaveric donors, while almost all of the remainder have been donated by living relatives. More recently, a small proportion of transplants has involved living, unrelated donors.

Significant advances have come about, especially in recent years, which have made it possible to expand the criteria of acceptability for patients who desire to receive kidney transplants. The availability of more effective drugs to suppress the immune system of the transplant recipient, thereby reducing the likelihood of rejection, has made it evident that many patients are suitable transplant candidates today who would not have been considered in the past. The most significant of these newer drugs is cyclosporine, which until now has been used primarily for recipients of cadaveric transplants, but which is being utilized with increasing frequency for recipients of related and living, unrelated transplants as well.

It is anticipated that even greater numbers of transplants will be performed in the next few years, and undoubtedly in more centers than the approximate 200 which currently exist in the United States. However, it is also expected that many more patients will be treated with dialysis in the future. This care will also be given in more than the approximate 1,500 dialysis units which currently exist. In fact, it has been projected from some studies that the dialysis population will probably double by 1996 and will quadruple by the year 2006.

Related Donor Transplants

It is likely that more donor transplants will be performed in the future, and many of these will be carried out according to a donor-specific blood transfusion protocol which was developed at the University of California-San Francisco in 1978. This protocol has been applied primarily to related transplants in which the donor and recipient have a less than perfect tissue match, and in some additional cases when the donor and recipient showed no tissue match whatsoever.

According to this protocol, three transfusions (of relatively small amounts) from the prospective donor ("donor-specific transfusions") are administered to the prospective recipient. As blood is a living issue, this provides a means for exposing the immune system of the prospective recipient to the tissues of the prospective donor ahead of time. The response of the immune system to the tissues of the prospective recipient can then be studied with regard to whether or not potentially harmful antibodies are formed. Hence, the possibility of a successful transplant outcome (or failure) can be predicted before the transplant takes place. As more than 400 patients at the University of California-San Francisco have now received transfusions according to this protocol, it is clear that between 15-30% of them develop antibodies directed against the donor tissues which are potentially harmful. Consequently, such transplants are not performed, as they would probably have a high rate of failure. However, approximately 70-85% of the time when prospective recipients receive donor-specific transfusions, they do not make such antibodies and the transplant can be performed as long as the prospective donor is established to be medically suitable to donate.

The results for more than 350 transplants carried out according to this protocol at the University of California-San Francisco over the past ten years show rates of success at two years of approximately 90% and at five years of almost 80%. In addition, the results were statistically equally good regardless of whether the donor-recipient tissue match was poor or even if there was no tissue match at all. In fact, the results of such transplants involving a poor tissue match or no match at all were statistically no different when compared to more than 200 transplants of a perfect match in which the donor-specific transfusion method was not utilized.

It is noteworthy that approximately 20% of these transplants involved patients with kidney failure as a consequence of diabetes. In addition, when the diabetic and non-diabetic recipients were compared, no significant differences in the rates of success were observed. Hence, the results of such transplants make it evident that if the donor is a living relative, the quality of tissue match between the donor and the recipient is not the most critical factor, as long as compatibility exists. Rather, the most important consideration is the manner in which the transplant is carried out, which in turn is largely determined by the quality of tissue match. That is to say, the donor-specific transfusion protocol appears to be most useful when applied to transplants in which the donor and recipient have a poor tissue match or no match at all.

Nicholas J. Feduska, M.D., is Professor of Surgery and a kidney transplant surgeon at the University of California, San Francisco.

Living Non-Related Donor Transplants

Once it became evident that the donor-specific transfusion method could be applied successfully to related transplants of no match at all, the question was raised as to whether the same technique could be applied to transplants involving living donors who were unrelated. Such transplants involving living, unrelated donors are still considered to be investigational, even though a number were performed in the 1950s and 1960s. The success rate for these earlier transplants was poor, so for ethical reasons it became unacceptable to recommend that such transplants be carried out. However, the excellent results associated with the donor-specific transfusion protocol have made it possible to reconsider this approach.

At the University of California-San Francisco and the University of Wisconsin, there has been a combined experience of 42 living, unrelated donor transplants performed over the past six years utilizing donor-specific transfusions. All but six of these transplants are functioning, and the patient survival rate until now is greater than 95%. In addition, a number of these recipients had kidney failure associated with diabetes. The donors included spouses, friends, a stepfather, a stepmother, a brother-in-law, a sister-in-law, and a father-in-law. Significantly, the quality of kidney function associated with these transplants was no different when compared to related donor transplants performed in these same centers. Furthermore, none of these donors died or experienced any serious long-term complications as a consequence of donating.

Because of the risks involved, everyone does not agree that living donors should be accepted for kidney transplantation. It has been estimated that approximately 20 living donors have died either as a direct or indirect consequence of kidney donation. The donor operation is a major procedure and is associated with the same risks as all other major operations; but death of the donor is highly unlikely in centers with specialized teams and considerable experience.

Concerns have also been expressed by some that living donors may later be at increased risk for the development of kidney disease (in their remaining kidney) and high blood pressure. Although such concerns have been justified by both theoretical considerations and experiments involving laboratory animals, most of the reported studies to date involving the long-term follow up of living donors do not support this concept. Hence, in most centers living donors continue to account for the source of kidney transplants between 30-50% of the time.

Living, unrelated donor transplants are recommended only in special circumstances. They are typically reserved for those exceptional cases when a related or cadaveric donor cannot be identified. The motives of the donor must be genuine and in the best interest of the recipient, and not self-serving or for profit. An independent evaluation of the living, unrelated donor is performed in order to assess their motivation as well as their medical and psychologic suitability. Frequently, a donor advocate is also assigned to help counsel the prospective donor, in addition to the usual counseling provided by members of the transplant team.

The idea of living, unrelated donor transplants is appealing to some because it provides the possibility of avoiding the long periods of waiting that might otherwise be necessary for compatible cadaveric donors to be identified. Such long periods of waiting may be especially significant for diabetic patients on dialysis, who frequently experience progressive deterioration of their vision (diabetic retinopathy), progressive neuropathy (abnor-

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Advances in Kidney Transplantation

(From page 3.)

mal function of the sensory and motor nerves), and other significant medical events as well. In addition, it is theoretically possible that living, unrelated donor transplants will ultimately prove to give higher rates of success than those which are currently associated with cadaveric transplants.

The mechanism by which donor-specific tranfusions achieve these high success rates, even for transplants of a poor tissue match or no match at all, is still unknown. It is possible that such transfusions, representing donor tissue, may alter the immune system of the recipient directly, resulting in greater acceptance of the transplanted organ. It is also possible that such transfusions serve as a kind of provocative test of biologic selection, permitting the identification ahead of time of those transplants which are likely to succeed and those which are likely to fail. If the latter concept is correct, the use of this technique makes it possible to perform those transplants which are likely to succeed, while avoiding those which are likely to fail.

Cadaveric Donor Transplants

Approximately 60-70% of kidney transplants are made possible through the use of cadaveric donors. It is anticipated that even greater numbers of such transplants will be performed in the future. In addition, as better methods of donor management come about, and as techniques and methods of kidney preservation improve, the rate of success for cadaveric donor transplants will undoubtedly improve further. Increased public awareness of the need for donors will also contribute greatly to making many more donors available in the future. A Gallup poll conducted some months ago showed that almost 95% of U.S. citizens were aware of the potential benefits of organ transplants, and 75% indicated their willingness to give consent for donation by a relative if death of the relative occurred in a circumstance which made donation possible.

There is universal agreement that many more potentially suitable cadaveric donors exist than are actually serving as donors. It has been estimated that in the United States alone there are approximately 24,000 potential donors each year. As almost all of these donors have two kidneys, approximately 48,000 cadaveric kidney transplants per year are theoretically possible. These would more than satisfy the needs of the many patients who are currently awaiting such transplants.

Some additional factors which should make more cadaveric kidney transplants possible in the future are the routine request and routine inquiry laws, which were formerly enacted in a number of states, and which have subsequently become federal law. Hospitals are now required to have mechanisms in place for identifying potential donors, and for presenting the possibility of donation to family members of deceased individuals at a time when, because of their grieving, they might otherwise overlook this possibility. Such laws enhance the likelihood that transplant teams will be able to carry out the expressed wishes of the deceased individuals and/or members of their families.

As more cadaveric transplants are performed and as greater experience is gained, fewer transplants will be lost because of avoidable technical complications and rejection. The incidence of vascular complications (relating to the blood vessels of the transplant which are surgically attached to the blood vessels in the recipient), and other problems such as leakage of urine from the ureter of the transplant or the urinary bladder, should be reduced to an occurrence rate of less than 2-3%. Techniques such as flow cytometry, which can often detect the presence of antibodies with a degree of sensitivity 200-300 times greater than that which was previously possible, will also contribute greatly to improving the success rates and to reducing the number of kidneys lost because of rejection.

Cyclosporine has already dramatically improved the success rates for cadaveric kidney transplants, and in some cases has been useful in related donor transplants as well. It is likely that other immunosuppressive drugs will become available in the future which will have an even more specific effect on the immune system than was the case in the past. Consequently, patients who will be treated with cyclosporine or similar drugs in the future will probably be more likely to have their tendency toward rejection controlled, while at the same time being less susceptible to infections than previously.

The use of cyclosporine in combination with prednisone as the primary mode of immunosuppression for recipients of cadaveric kidney transplants at the University of California-San Francisco has improved the success rates by approximately 30% in the last four years alone. The success rates for 375 consecutive transplants of this type in which the recipients were treated with the combination of cyclosporine and prednisone, for example, were 79% at one year and 72% at three years, compared to 50% at one year and 40% at three years formerly when other, less-specific immunosuppressive drugs were utilized. In addition, an analysis of the more recent experience shows that patients in higher-risk categories, such as those with diabetes, now have essentially the same chance for success as patients in lower-risk categories.

For example, when 60 diabetic patients who received a first cadaveric transplant were compared to 278 non-diabetic patients who received a first cadaveric transplant, no significant differences were observed in the success rates at one to three years. In addition, older recipients of cadaveric transplants (for example, over 50 or 60 years) showed no significant differences in success rates when compared to younger recipients, and neither were any significant differences observed when recipients of first cadaveric transplants were compared to recipients of second and third cadaveric transplants. It was also observed in this recently analyzed experience that those patients who had received random-donor transfusions before their transplants had a significantly higher rate of success when compared to recipients who had never been transfused. This observation has also been made in many other transplant centers, and indicates that higher rates of success for cadaveric transplants can often be achieved by simply making certain that the recipients have received at least a small number of transfusions prior to receiving their transplants.

Two of the cadaveric kidney transplant recipients at the University of California-San Francisco, who were treated with cyclosporine and prednisone as their primary mode of immunosuppression, had also received heart transplants earlier. One of these is a man who received a heart transplant in 1974, in treatment of heart failure associated with coronary artery disease. He developed kidney failure and received a cadaveric kidney transplant in July of 1985. He is alive, has normal kidney function, and until now has experienced no episodes of rejection whatsoever. The second patient is a man who received a heart transplant in 1982, in treatment of heart failure caused by a viral infection. He subsequently developed progressive rejection of his heart transplant, and kidney failure as well. In July of 1986, he received a second heart transplant, and 54 hours later received a kidney transplant from the same donor. The current status of this patient is that he is alive, has normal kidney function, and has experienced only one mild episode of rejection approximately two weeks after his transplant was performed.

Because of improving results such as these, it is probable that in the future more patients with kidney failure will be considered as candidates for transplants earlier in the course of their disease. This may contribute to further enhancing the quality of their lives. Patients who have kidney failure associated with diabetes will undoubtedly be significantly influenced by such a trend.

Unfortunately, it can also be anticipated that the list of patients awaiting cadaveric transplants will become even longer in the future, as it is likely to include more younger and older patients, as well as more patients in various other higher-risk categories who formerly might not have been considered to be suitable candidates. It is also probable that there will be many more patients whose lives are sustained by multiple types of organ transplants simultaneously.

Summary

It is the sincere hope of everyone involved in caring for patients with kidney failure and diabetes that the significant improvements which have already occurred, and the anticipated future changes which have been alluded to, will make possible even greater prolongation of life, improvements in the quality of life, and effective rehabilitation than was ever possible in the past.

The Promise of Cyclosporine

(From page 2.)

Today cyclosporine is widely considered the drug of choice for kidney transplants. By early 1985 more than 8,000 kidney transplant patients had received cyclosporine.

Are There Side Effects?

In animal studies, cyclosporine produced only minor side effects. Nevertheless, the animal work failed to warn of a number of side effects that appeared once the drug was tested in humans.

Kidney damage is the most significant side effect of the drug, but it has been found that lower doses of cyclosporine can eliminate the danger of any damage.

Liver damage affected some early transplant patients. Once again the dosage of the drug was lowered and the problem decreased sharply and is no longer considered a major concern. Hirsutism, or increased hair growth, appears in about one of four patients taking the drug. Overgrowth of the gums, high blood pressure and tremors have been noted in ten to 30 percent of patients.

What Is the Future of Cyclosporine?

Cyclosporine potentially represents the first in a new class of drugs. As an immunosuppressant, its activity is unique and will certainly stimulate the research for other immunospecific agents. We can look forward to many more specialized immunosuppressive drugs in the future. It is hoped a form of cyclosporine may be developed which will destroy parasites without suppressing the entire immune system, leaving the patient vulnerable to other infections. The prospect of such achievements is extremely exciting to the scientists working on cyclosporine today as well as to the practitioners and beneficiaries of modern medicine.

Some Men Dream Dreams That Never Were And Ask, Why Not?

This characterization aptly portrays that modest assembly of blind persons which convened in 1940 in Wilkes-Barre, Pennsylvania, to establish the National Federation of the Blind. Summoned together by a brilliant young constitutional lawyer, Dr. Jacobus ten-Broek, who was to serve as the organization's founding President, these pioneers were few in number and lacking in financial resources.

But they *did* have a dream — and that was what made all the difference. At a time when most blind Americans lived in a twilight zone of poverty and unemployment, they foresaw a day when those of our citizens who are blind would participate in society on a basis of equality with their sighted neighbors, as producers in the economy, as advocates for enlightened public policy, as brothers and sisters who share full measure in the joy and pain of interpersonal relationships. Abundant life, whose "cup runneth over" —lives of fellowship, hope, compassion, and commitment — such a life these pathfinders deemed to be the birthright of every blind American.

The founders of the Federation knew that there was nothing about the absence of sight — or the ability to see a little — which must determine that blind persons allow their dreams to be deferred, or reside in a ghetto of second-class citizenship. They understood that with proper training, the absence of sight could be reduced to the level of an inconvenience, a nuisance.

What had to be changed were archaic and outmoded public attitudes — preconceptions often clung to by those who are blind, as well as those who see — that kept blind persons on the sidelines, rather than in the mainstream of society, and perpetuated custodialism and dependency.

Since 1940, progress has occurred in giant strides. Blind persons have entered the professions and government service in large numbers, and have excelled in nearly every facet of private industry. As the walls of Jericho crumbled before the trumpet call of Joshua, the barriers of discrimination have fallen before the conscience of a nation aroused by the *blind speaking for themselves.*

Much has been accomplished, yet much remains to be done. How? If not by us, then by whom? If not now, when? As Harvey Cox once put it, "Not to decide is to decide."

To serve as an agent of change guarantees little in the way of personal comfort or security. You will have to work hard, to persevere, to stick your neck out. What you get in return is the thrill and pride of really making a difference. If this is what you want for yourself and for your fellow blind, please contact the National Federation of the Blind.

Transplantation, Why?

from Kidney Kazette, Sept., 1984 p.4 (Columbia, MO: Dialysis Clinics, Inc.)

There are 13 million Americans, young and old, with kidney-related diseases. Not all of these diseases mean total kidney failure. Some kidney diseases can be cured. They are acute or temporary in duration. But some kidney diseases result in total, chronic kidney (renal) failure, which, without treatment, means death within weeks.

Total renal failure simply means the body does not eliminate waste and fluid through the urinary tract and does not regulate critical functions like blood pressure and red blood cell production, among others. A few decades ago, total chronic renal failure meant death, but medical science has changed that picture forever. Patients with chronic renal failure now literally have a new lease on life through dialysis and transplantation.

Dialysis is the filtration or cleansing of the blood using an artificial kidney (hemodialysis) or by introducing an internal dialysate (peritoneal dialysis). Hemodialysis patients spend 10 to 18 hours every week on a dialysis machine to rid their blood of toxic waste and fluids. But hemodialysis, even though it is life-sustaining, does not accomplish the complex job nature intends for the kidneys. Hemodialysis patients battle chronic anemia, weakened bones and hypertension; they follow a restrictive dietary and medication regimen. In children, normal growth rate is adversely affected.

A newer form of dialysis, continuous ambulatory, peritoneal dialysis (CAPD), offers the patient more freedom and avoids certain complications associated with hemodialysis. Yet, CAPD is not free from complications — and the long-term effects of CAPD are still unknown.

While dialysis is the therapy choice of some patients, for others dialysis is only life-sustaining while they await a kidney transplant.

Transplantation: What is it?

Kidney transplantation is a surgical procedure which removes a healthy kidney from a donor and implants that kidney into the recipient (or, renal patient), connecting the donor kidney to arteries, veins and bladder so that it may resume the job nature intended.

What Happens When the Transplant Works?

Successful transplantation is practically a medical miracle. Successful transplant recipients' lives come around full circle from a state of life-threatening illness to renewed health and well-being. For children, a successful transplant means regaining energy and good health instead of illness, returning to a normal growth rate and to full-time school and play participation — all so necessary to childhood development. A successful transplant has all these meanings and more.

What is Rejection?

Rejection is the body's natural response to foreign tissue and the major impediment to a 100% success rate in kidney transplantation. The rejection rate for living related kidney donations is low (10-30%); in cadaveric donations (donations from unrelated persons made after death), the rejection rate is somewhat higher. All transplant recipients take "immunosuppressants," or drugs that decrease the body's naturally strong immune system.

(Editor's Note: According to current data compiled at the University of Minnesota Transplant Center, a two-year follow-up of patients using cyclosporine showed the following success rate: perfect-match relative kidney donations 100%; other relative kidney donation 95%; cadaver kidney donations 90%.)

What Happens if the Transplant Fails?

The patient returns to dialysis, and another transplant may be considered. In some cases, a second or third transplant will be the successful one.

If I or a Member of My Family Needed Transplant, Would We Easily Get One?

Only two of every 10 chronic renal failure patients have acceptable living related donors with blood and tissue-type matches. For a transplant, then, eight of every 10 patients have to rely on organ donations made by anonymous, unrelated donors who have died.

Is There a Waiting Period, Then, for Transplantation?

Yes, but sometimes the donor kidney never comes. Sometimes the dialysis patient develops complications of renal failure and dies before a successful transplant can occur. There simply aren't enough donor kidneys for every patient wanting and needing one.

Even though most of us have living relatives ... even though each cadaveric donation means two available kidneys for transplantation to two kidney patients ... even though each of us has the moral and legal privilege to donate our organs ... there still aren't enough donated kidneys.

Who Can Donate Kidneys?

Anyone 18 years of age or older may donate to a relative or donate after death. Deceased minors can become organ donors with parental or guardian consent; minors are rarely living donors. A living donor must be related to the patient. That donor will give one kidney; for donor and recipient, one kidney each has the ability to do all the work nature intended for two. Living related donors, like successful transplant recipients, are expected to lead fully productive, healthy and normal lives after a short period of recuperation from surgery.

Who Actually Performs the Transplant?

Local transplantation teams of surgeons, nephrologists, nurses and technicians ... specially skilled members of your own medical community.

Are All Donated Kidneys Used?

Every living related donation is, of course, transplanted. Every effort is made to transplant both cadaveric donations within a 48-hour time limit. That time limit allows the optimal chance for a successful transplant. Assisting the transplant team in this effort is the latest technology: a nationwide computerized network listing potential recipients, transportation networks, and the kidney perfusion machine which maintains the donor kidney in the ideal state for transplantation for 48 hours.

Does Cadaveric Organ Donation Interfere in Any Way with Normal Burial Practices?

No, it does not.

Is There Any Cost to the Donor or Donor's Family?

Medicare pays all medical costs incurred in organ donation. There is no cost to the donor or to the donating family.

What Can I Do to Become an Organ Donor?

Obtain a uniform donor card from your National Kidney Foundation, sign and witness it. If your state includes a donor card on the back of your driver's license, sign and witness it. Both are legal documents. Most importantly, talk to your family and let them know you have made the personal decision to be an organ donor. Ask them to assist you by carrying out your wish to pass life on to others.

Go For It!

by Charlotte Verduin

This article is written to encourage anyone in need of renal transplantation to put aside fears, become as informed as possible, and then in all haste get on a recipient list. There is no substitute for the health achieved after a transplant. Perhaps others are trying to make the same decision I had to make under similar circumstances and will be heartened by reading the following.

People with diabetes age faster than people who don't have this condition. Because diabetes is a condition of abnormal blood sugar control, and the blood stream affects *all* the other systems in a body, there is no way to guess where or when complications will develop, or how severe they will be. I want to share part of my diabetic history to give strength, hope, and a bit of positive philosophy to other diabetics.

I've been a diabetic for 27 years, diagnosed at age 11. During high school and early college, I practiced minimal control over my diabetes — a very common development among diabetics in adolescence. As I matured and took responsibility for my life and for the complications beginning to affect my life, I did better at controlling blood sugars and reactions. I was lucky that my prolilerative retinopathy stabilized before legal blindness. Neuropathy has affected my feet, making them insensitive to pain and decreasing my balance. Sclerosed blood vessels in my extremities have limited my agility. In 1979 I survived a pregnancy (which is *another* story) and have an exceptional eight-year-old daughter to further motivate my taking good care of myself.

In the spring of 1985, I had an infection in my left foot, and immediately upon recovery broke a bone near the infection site. I was treated with intravenous antibiotics which were toxic to my kidneys causing end-stage renal disease with less than 20% function in each kidney. My kidneys had been healthy previously, so this information came as a great shock. Unfortunately, I needed time to adjust to the idea of renal failure and the inevitability of it all. In hindsight, I wish I had not allowed my fears of major surgery to keep me from considering a transplant earlier. The healthier one is before a transplant, the healthier one continues to be afterwards. Few lay people urge transplantation; the prevailing feeling is to put it off as long as possible. Time is the enemy. Diabetes affects all body systems, bringing about an abnormal condition in the blood; in the same way, kidney failure causes "poisons" in the bloodstream to travel to *all* systems, doing their little-by-little damage. Dialysis helps as insulin helps: it prolongs life — but it doesn't come close to a cure.

My daughter happens to be blind, and through joining the National Federation of the Blind (NFB) for her, I found its Diabetics Division to be a support group for myself. The people in the Division who had undergone transplants were a great help to me as I struggled with the idea of having one. They said it meant a nearly normal life style again. So, having gained courage from members of the Diabetics Division of the NFB, I went onto the transplant list in St. Louis. By incredible good fortune, I received my first transplant only 10 days later.

This operation went very well. I was amazed and pleased at how quickly I recovered and how minimal the discomforts and complications were. I left the hospital 11 days after admission. My new kidney was working so well that I felt better than I had in several years. My cheeks were rosy, my skin was healthy. My energy level was bouncy and so were my spirits, and my mental processes were sharp — unlike they were on dialysis. After three weeks, however, this kidney failed. I returned to dialysis for six months until another kidney match could be found.

The second operation went as well as the first, and my new kidney is working even better than the first. But after six months on dialysis, my body was less resilient than it had been before. I suffered through several minor complications, some of which still plague me. But I am thankful every day for the advancement of science and the generosity of strangers that have so improved my life. The benefits of kidney transplantation far out-weigh the operation.

I know how terrific a new kidney can make you feel; I know what an incredible difference it can make to a life. An organ donation is beyond a "thank you," it truly gives new life. And so, my message is this: Encourage organ donation among your relatives and friends. And, if you are a diabetic with kidney failure, seriouly consider a transplant. Find out as much as you can from your physicians, and from members of the Diabetics Division of the NFB, who can tell you first-hand what the transplant experience is all about. It can mean a much healthier, happier, longer life!

We've Moved!
Please note:
Voice of the Diabetic
has a new address:

811 Cherry Street
Suite 306
Columbia, Missouri 65201
(314) 875-8911

If you or a friend would like to remember the National Federation of the Blind in your will, you can do so by employing the following language:

"I give, devise, and bequeath unto National Federation of the Blind, 1800 Johnson Street, Baltimore, Maryland 21230, a District of Columbia nonprofit corporation, the sum of $_____ (or "_____ percent of my net estate" or "the following stocks and bonds: _____") to be used for its worthy purposes on behalf of blind persons."

New Transplant Findings Fit Like a Glove

by R. Weiss

This year more than 10,000 kidney transplants will be performed in the United States, according to the National Kidney Foundation. But despite recent advances in immunosuppressive therapy (SN: 6/28/86, p. 407), approximately 20 percent of these transplants will result in rejection — most them in patients who at some time in their past have tested positive for human lymphocytic, or HLA, antibodies.

Physicians have known for years that a patient with HLA antibodies specific to a donor's HLA antigens is much more likely to reject that donor's transplanted organ. Indeed, with donated kidneys in short supply, anyone who has *ever* tested positive for these antibodies is considered a poor candidate for the lifesaving surgery — even if, as often happens, their antibodies inexplicably disappear at some point. Surgeons willing to perform transplants on such "historically positive" but currently HLA-negative patients have been frustrated by their inability to understand why some of these grafts are in fact very successful, while others are almost immediately rejected.

Recently, however, researchers have found evidence of a multi-tiered anti-antibody system that not only explains why HLA antibodies sometimes disappear, but also identifies HLA-converted patients for whom transplants will probably succeed. Like a series of bigger and bigger gloves fitting over an original hand, the anti-antibodies and anti-anti-antibodies — both known as anti-idiotypic antibodies — apparently will either block or potentiate a patient's original HLA antibodies. Their discovery, reported in the June 4 *New England Journal of Medicine*, may lead to changes in the way patients are tested for organ compatibility and could lessen the uncertainty inherent in the transplant business, scientists say.

The research team, led by Elaine Reed at Columbia University's College of Physicians and Surgeons in New York City, performed retroactive blood tests on 20 kidney recipients with histories of antibody sensitization to their donor's HLA antigens. Half the patients rejected their transplants within 30 days, but the remaining 10 patients' grafts survived at least one year, despite no apparent significant differences between the two groups' immunological compatibility. With further testing, however, the researchers found that nine of 10 patients whose grafts were successful showed evidence of anti-antibodies capable of blocking their original HLA antibodies. Moreover, nine out of 10 of the patients who rejected their grafts showed evidence of anti-anti-antibodies, which seem to overwhelm the anti-antibodies, thereby reinstituting the original immune reaction.

"This is the most important finding I can think of to explain the loss of antibody in some sensitized (kidney transplant) patients, and to explain why some patients do well and others do not," Reed says. The test will be of particular benefit, she suggests, to the approximately 30 percent of would-be transplant recipients with a history of being highly sensitized to HLA antigens. Anti-idiotypic antibody testing, she says will show that many of these patients who have until now been considered poor transplant candidates may in fact be ideal recipients. Similarly, would-be recipients who at first appear to be donor-compatible but who harbor undetected anti-anti-antibodies can be identified and spared the medical and economic expense of a transplant that is almost certainly doomed.

Thomas Fuller, a blood transfer specialist who is doing related research at Massachusetts General Hospital in Boston, says Reed's findings are significant not only because they open the door to better compatibility testing, but also because they may lead to sophisticated ways to induce antibody-specific immunosuppression in transplant recipients. "We all hope that someday we'll know enough about the immune system apparatus to allow us to manipulate it," he says. "If we could design or stimulate production of anti-idiotypic antibodies, it would probably allow transplants for many of the patients who have antibodies that now preclude them from getting organs." Such capabilities, he says, are still years away.

Meanwhile, Reed says of the two-hour test, "To have a tool that tests for an antibody associated with rejection is very important. Our goal is to implement these tests as routine clinical procedures on all our kidney transplants."

(Note: Reprinted with permission from *Science News*, the weekly news magazine of science, copyright 1987 by Science Service, Inc.)

Pertinent Data About Kidney Transplantation and Dialysis

by Ed Bryant

According to a pamphlet issued by the National Kidney Foundation (NKF), there are more than 90,000 kidney patients on dialysis, and approximately 80,000 Americans die each year from kidney and urinary tract disease. Statistics show that from 25% to 30% of patients on dialysis are diabetic.

Some diabetics think they are safe on dialysis and do not choose to have a kidney transplant. They do not like the risk involved in undergoing major surgery and fear losing their kidney. Some tell themselves that there might be a medical breakthrough and their kidney function restored. However, once the kidney is severely damaged from kidney disease due to diabetes, there is absolutely no way it can be restored or made to function again. A kidney is an extremely complex organ, and there is little chance that an artificial kidney will be developed in the near future.

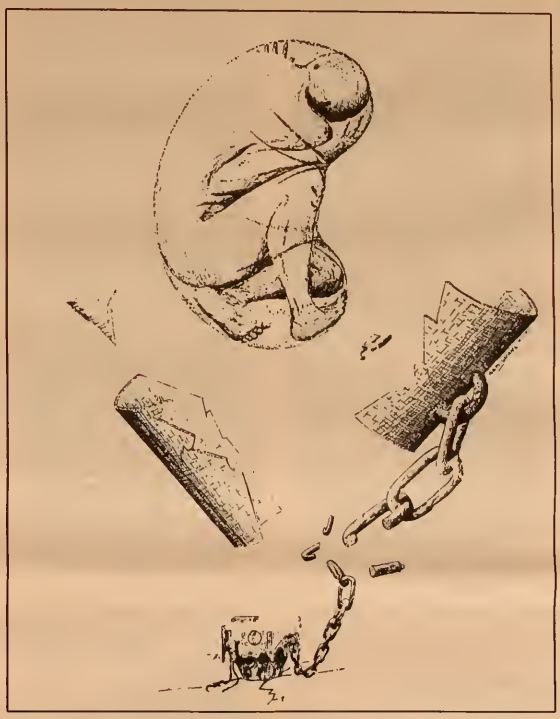
Following are some revealing facts about diabetics who undergo dialysis:

1. .Prior to 1980 not many diabetic patients underwent dialysis treatments, and the mortality rate for those who did was high.
2. Today, with improved medical techniques, the mortality rate for diabetics on dialysis is still high but not nearly as high as it was prior to 1980.
3. Statistics make it obvious that cardiac status and age are often the determining factors of how long the diabetic patient will survive.
4. The diabetic dialysis patient spends an average of 30% more time in the hospital than does the non-diabetic dialysis patient.

Some people, due to age and/or medical conditions, cannot have a transplant, and some people do not want one. A diabetic on dialysis can survive by closely adhering to the many rules that must be followed to correctly dialyze or filter the system. But, visit any dialysis unit and the pain, suffering, and anguish will be obvious. Not everyone on dialysis experiences pain, but many do.

Dialysis patients must follow a rigid diet; there are many foods they cannot eat, or at least in very limited amounts. They are allowed very little liquid of any type and must closely watch their salt intake since salt retains liquid. They should not indulge in high sodium foods, such as soups or luncheon meats and must watch their postassium intake, limiting such foods as bananas and oranges.

Either due to age or medical condition most dialysis patients are not employed. A person on hemodialysis must be hooked up to a machine three times a week from 3½ to four hours each treatment. Many patients feel weak and nauseated after their dialysis treatment and can do very little for the remainder of that day. This means these people are incapacitated three days every week.



Nicole Gemignani from Nimes, France, was at the Kidney Transplant Games in September of 1987 at Innsbruck, Austria. (See article "Transplant Games ...," on p. 20). This is the illustration she drew depicting how much better people feel after breaking away from dialysis through kidney transplants.

Continuous ambulatory peritoneal dialysis (CAPD) is another form of dialysis treatment which works out well for some people. Surgery is required. A tube is inserted into the peritoneal cavity which allows the urine and unneeded body substances to drain into a bag secured around the waist.

For more information regarding kidney transplantation vs. dialysis, I encourage you to review other articles in this issue of *Voice of the Diabetic.*

I am a strong advocate of kidney transplantation. I have had my kidney for almost 4½ years, and I feel just great. Perhaps you should have a transplant and perhaps you should not. Many people do not know if they should "go for it" or not. Today the graft survival rate is better, partially because of Sandimmune (cyclosporine). Cyclosporine is an immunosuppressive drug, and all kidney transplant patients must use immunosuppressive therapy for life. Today's statistics show that the first-year survival rates for kidney transplants are 75% for a cadaver-donor kidney and better than 90% for a living related-donor kidney. All surgery is risky, but the success rate in kidney transplants is high.

I do not mean to give the impression that people who have had kidney transplants have no problems. A study carried out from January 1, 1978, through June 30, 1983, in which all institutions in the upper mid-west region of the United States cooperated, concludes there is "no survival difference between patients undergoing transplantation, CAPD, and hemodialysis, *if* simple corrections for differences of age are performed," and there is a higher prevalence for limb amputation after transplantation. (Marcel Legrain, M.D., et. al., "Selecting the Best Uremia Therapy," in *Diabetic Renal-Retinal Syndrome, v. 3 Therapy,* ed. Eli A. Friedman and Francis A. L'Esperence, Grune and Stratton, 1986).

On the other hand, an article entitled "An Assist for Dialysis" printed in the November 10, 1987, issue of the *St. Louis Post-Dispatch* stated that "Transplants are the best treatment for patients who are good candidates for surgery because a transplant frees a patient from many hours of dialysis each week, permitting a nearly normal lifestyle." I know many kidney transplant recipients who say unequivocally that a kidney transplant is the only way to go. The people I know who have lost their transplanted kidney want another transplant.

After my kidney transplant, I was in the hospital eight days. I had no rejection episodes, although there are quite a few who do undergo kidney rejection. Rejection, however, does not necessarily mean the loss of the new organ; it often means only that extra days or weeks must be spent in the hospital. After a kidney transplant, the first year is the most critical time. At first you are very immunosuppressed so your body is unable to defend itself as well as it normally does. Immunosuppressive drugs suppress the immune system making you more susceptible to colds, the flu, and other infections. With time the immunosuppressants will be decreased and you will not have to be as worried about kidney rejection.

How long will the new organ last? There are people who have had a new kidney which has lasted more than 27 years. I have a diabetic friend who has had a new kidney for over 12 years and is doing just fine.

As I said earlier, I strongly endorse kidney transplantation, especially for the diabetic. Four and one-half years after my transplant I find myself stronger both physically and mentally. My quality of life is much better. I am active and productive doing and enjoying the things that I did before I began to experience severe renal failure.

What are some of the advantages to kidney transplantation as opposed to kidney dialysis? A better quality of life, not being dependent on a machine, and lower annual medical costs are some of the benefits.

A person with a transplanted kidney usually feels much better than a person on dialysis who is constantly going into and being brought out of a state of chronic uremia. The survival rate of diabetics with transplanted kidneys is without a doubt much higher than that of dialysis patients.

There is very little, if any, cost for having a kidney transplant. Currently, the cost of the operation is funded by the Social Security Administration. Fund-

(Continued on page 10.)

I Believe In Miracles

by Sherrie Turner

Sherrie Turner is a long-term diabetic who has experienced complications of diabetes. A kidney transplant has given her "a chance at a normal life" and she now feels great.

I *do* believe in miracles. That belief in miracles and God's power working in our lives is a very large part of my philosophy of life. That belief has sustained me for the last three years. But I also have a great belief in the power of medical technology and knowledge through which many of us have been given the gift of new life.

My particular miracle has been made possible through organ transplantation. I have been the recipient of two kidney transplants within the last two years, and I know firsthand that transplanted organs can give a wonderful new lease on life.

My doctor diagnosed me as an insulin dependent diabetic in 1964 when I was ten years old. My steadily worsening condition forced me to begin dialysis in March, 1985. I had been losing my health and strength so gradually that I didn't notice the loss and thought everyone felt the way I did. Only after dialysis cleansed my system did I realize how much better I could feel.

But life on dialysis is not really life. I was tied to a machine, and the days that I wasn't dialyzing, I didn't feel well. Nevertheless, I felt better than I had before dialysis, and I was thrilled with the new feelings of strength and health I was experiencing even though they were dependent on the 3½ hours I spent hooked to a machine three days a week.

My doctor suggested kidney transplantation; my mother was willing to give me one of her kidneys, and we decided on August 15, 1985, as the date for the surgery.

After the kidney transplant I felt so invigorated and energetic that I was sure a major miracle had occurred in my life. I felt like doing things that I had not attempted for several years. Yet, as in most of life's situations, especially where medical procedures are concerned, there are no guarantees, and my first transplant wasn't to be my last. That kidney's performance was rather unstable from the beginning. In October, 1985, I suffered several breaks in my left ankle which caused problems with the new kidney. In December I suffered obstruction of the ureter requiring more surgery, further compromising the kidney. Finally, in July 1986, an abscessed tooth caused poisoning in my blood system, and my mother's kidney died.

Yet, as in so many cases of which I'm aware, the Lord was not finished with my miracles. On October 5, 1986, just before I was scheduled to be put on continuous ambulatory peritoneal dialysis (CAPD), my nephrologist, Dr. M. Roy First, called me to come to the University of Cincinnati Medical Center to receive a 24-year-old male cadaver kidney. The transplant took place the next morning, October 6, at 1 a.m.

From the beginning, this kidney has performed with a stability never achieved by the first one. The kidney, which at this time is nearly a year old, has maintained this stability despite a fungal infection of my right hand which required five months of chemotherapy.

Of course, a transplant is not like your own God-given organ. It requires a lifetime of medications to prevent rejection. These medications can have serious side effects, which include joint deterioration and increased risk of cancer. A transplant requires a close relationship with the doctor; in my case, it requires frequent 100-mile round trips to my doctor's office for blood glucose monitoring and careful scrutiny of every aspect of my health. Yet, even with these inconvenient changes in my lifestyle, my kidney transplant has given me a chance at a normal life. Thank God for every advance in medical technology and for the loving, conscientious doctors who implement them.

Thank God, too, for organ donors and their families. An organ donation turns a tragedy into a triumph, allowing life to spring from death. As many as six people can receive a new lease on life through the love and generosity of one organ-donor and his family. Organ donation is a new and widening frontier of medical technology and a wonderful way to show Christian brotherhood and love.

Do You Know a Diabetic?

We at the Diabetics Division of the National Federation of the Blind and our newsletter *Voice of the Diabetic* serve as a support and information network for all diabetics. We, of course, cannot replace the medical professionals; but we believe we can help in educational endeavors, and *you* can help in our outreach efforts. We cannot be of any help to the diabetics who might suffer the same complications we do if they don't know about us. We ask you to tell anyone you know, especially hospitals, agencies, or any other business which deals with diabetics, about us.

The paragraphs below describe us, and you will find information at the end of this article for ordering additional newsletters.

(You might subscribe for your own library and/or order a bulk stack for patrons or patients.)

We hope you look over our publication and find it well worth subscribing to, be it for your own use or as a reference for others.

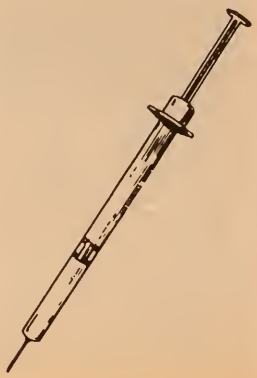
About the *Voice of the Diabetic* and the NFB Diabetics Division

We at the NFB Diabetics Division know that diabetes can either be devastating, or a mere nuisance which, if properly controlled, usually will not cause catastrophic problems. Yet we know, as most professionals do, that all severe diabetics are at risk. Therefore, we believe that all diabetics should be part of a good, loving and caring support network. They should be able to converse with "old hands" who "know what they are talking about."

It is often helpful for someone with a chronic problem to communicate with another person undergoing the same diabetic complication(s). We have members with every imaginable side-effect: blindness, amputations, renal failure, heart attacks, nerve damage, etc., who are more than willing to correspond with someone with the same problem. We also have members who have had no known complications.

Our main vehicle for disseminating information and letting our members' voices be heard is our newsletter. It is unique because of its positive, upbeat nature which is candid and personal.

We let people know they have options. For example, if someone has gone blind due to retinopathy, there is no need to hibernate and not be involved in the mainstream of society. There are instruments available so we, the blind, can accurately and independently draw up insulin, and there are also blood glucose analyzers with audio output so we can test our own blood sugar.



Positive attitudes are contagious, and we can always convey this thought. We provide a medium by which people can vent frustrations, since coping with diabetes can sometimes be difficult.

We have no paid staff (our work is done as a "labor of love") and realize no profit (the only charge is for production and handling). The officers of the Diabetics Division of the National Federation of the Blind are all long-term diabetics and each has undergone at least one diabetic ramification.

We hope you will join in our enthusiasm and arrange now to receive *The Voice* on a regular basis by subscribing today. Please refer to the subscription form.

Extra newsletters are available in units of five at a cost of $3 per unit. Please specify date, volume number, and the number of issues you would like. Send orders to:

VOICE OF THE DIABETIC
Editorial Office
811 Cherry St., Suite 306
Columbia, Missouri 65201
(314) 875-8911

What Is the National Federation of the Blind?

The NFB

The real problem of blindness is not the loss of eyesight. The real problem is the misunderstanding and lack of information which exists. If a blind person has proper training and opportunity, blindness is only a physical nuisance.

The National Federation of the Blind is the largest organization of the Blind in America. Interested sighted persons also join. Founded in 1940, the Federation has grown to include more than ten percent of the nation's blind (over 50,000 members).

The Federation is organized in every state and has local chapters in almost every community of any size in the nation. Where there is no local chapter, there are members at-large. Each year the National Convention of the Federation is attended by approximately 2,500 blind persons — the largest gathering of blind people in the history of the world and growing each year.

Purpose

The ultimate purpose of the National Federation of the Blind is the complete integration of the blind into society on a basis of equality. This objective involves the removal of legal, economic, and social discriminations; the education of the public to new concepts concerning blindness; and the achievement by all blind people of the right to exercise to the fullest their individual talents and capacities. It means the right of the blind to work along with their sighted neighbors in the professions, common callings, skilled trades, and regular occupations.

The Newly Blind

The newly blinded person faces a difficult adjustment. One of the best medicines is to meet other blind people and learn of their jobs and the techniques they use in doing things without sight. Membership in the NFB provides this common meeting ground and, even more importantly a sense of participation and restoration of confidence. Members of the NFB contact newly blinded persons to help them with problems of adjustment and orientation.

Information is also given concerning available services from governmental and private agencies, as well as facts about laws and regulations concerning the blind.

A Distinctive Role

The Federation corresponds to blind people in the same way that labor unions correspond to workers, the Chamber of Commerce to business people, the American Bar Association to lawyers, the NAACP to blacks, the American Medical Association to doctors, and the Farm Bureau to farmers. It is a vehicle for joint action by the blind. In other words, the National Federation of the Blind is the voice of the blind. It is the blind speaking for themselves.

Who Represents The Blind?

There are numerous governmental agencies and private charitable organizations and foundations providing services for blind people, but only the blind themselves (acting through their own organization, the National Federation of the Blind) are able to speak for the blind. This is a basic concept of democracy.

The government has a Department of Labor, but it cannot truly speak for workers. They speak for themselves. Like the Department of Agriculture does not replace farm organizations, nor do governmental agencies or private foundations take the place of democratic membership organizations of minority groups. This is true even if the agency or foundation is headed or largely staffed by members of the minority. As with others, so with the blind. More and more of the governmental agencies and private foundations are becoming responsive to the views and needs of the blind and are learning new concepts and attitudes about blindness. The future looks bright. There is an overwhelming feeling of goodwill and a wish to help on the part of the general public. Most important of all, the blind are moving forward to speak for themselves and take a hand in the management of their own affairs through their organization, the National Federation of the Blind.

Programs And Services

By means of speeches, pamphlets, radio, and TV appearances, members of the NFB strive to educate the general public to the fact that the blind are normal individuals who can compete on terms of equality with others.

The *Braille Monitor* is a monthly publication of the NFB devoted to news and discussion of issues important to the blind. It is published in Braille, in print, and on record or cassette, and is available to the blind and the sighted alike upon request.

Detailed studies of state programs for the the blind are carried out by the NFB when officially requested by state governors or legislatures.

Scholarships are awarded to blind students. Assistance is given to blind persons who are the victims of discrimination or whose rights have been denied. Such assistance takes the form of initiating court action, negotiating with public officials, conferring with private groups or individuals, and seeking publicity in the press and otherwise.

Future Reflections is the NFB magazine for parents of blind children. Through this magazine and other means, the blind of this generation reach out to offer help and encouragement (through parents) to the blind of the next generation.

New state and federal laws and regulations concerning the blind are researched. The blind are informed of services available to them and of their rights under the law. Consultation is provided to congressional committees and state legislatures, as well as to federal and state administrators. Local and state leaders of the blind from throughout the country are brought together for seminars to give them information to take back to their home communities and pass on to others. The Federation recently promoted and helped develop and evaluate a reading machine which translates the printed page into spoken words. Other new technology is also being evaluated and promoted. In short, the National Federation of the Blind is prepared to improve the lives of the blind.

Job Opportunities For The Blind

The NFB works to insure that training in the techniques necessary to function efficiently without sight is available. Some kind of training is available in every state, but often it leads only to sitting at home, or making brooms in a sheltered workshop for less than $1.00 an hour.

Blind people today work as lawyers, psychologists, machinists, farmers, hairdressers; but the best estimates indicate the 70 percent of those who are able to work still do not have jobs or work only a few days a month in sheltered workshops. Many thoroughly capable blind persons have never had a job.

To respond to this critically high unemployment rate, the National Federation of the Blind, in cooperation with the United States Department of Labor, developed a program of Job Opportunities for the Blind. JOB helps qualified blind people who are looking for work find employers with job openings. JOB also helps employers who have affirmative action requirements for hiring the handicapped find truly qualified employees, not just token blind people to meet a mandated government order. JOB conducts educational seminars about blindness for employees, and career planning seminars for unemployed blind people.

Protection Of Rights

There are barriers to full participation in society by the blind. The National Federation of the Blind stands ready to help blind people overcome these barriers when collective action is necessary.

Many blind mothers and fathers are currently experiencing challenges from social service agencies who want to take their children. The recent increase in the number of such reported instances reflects not just an increase in government meddling or custodialism (although there is plenty of that), but heightened awareness and determination to take action on the part of the blind and their friends.

The National Federation of the Blind is responding to the challenge. A blind mother in Florida is once again busy raising her child without interference from a social service agency. The agency backed down when the National Federation of the Blind came to her defense. Several cases are currently underway in which blindness is

(Continued on page 23.)

My "Transformation"

by Betty Walker

I was born in 1953 in Dover Plains, New York. I became diabetic at the age of five. My childhood was more or less "normal." I graduated from high school in 1971 and earned an A.A.S. degree in Nursery Education in 1973 from Dutchess Community College in Poughkeepsie, New York. My problems began at this time.

Before the end of 1974, I was totally blind; the causes being diabetic retinopathy and glaucoma. In January of 1978 I was confronted with renal failure. After coping with losing my sight, which I took day by day thanking God for each day, I felt this was just another of life's hurdles that I had to jump over. If I could not jump, I would climb; no matter how slowly I had to climb.

Most of the time while on dialysis I was very ill, I could not eat because I was so nauseated. My social life was non-existent. I no longer enjoyed any hobbies. I was so tired that most of the time between dialysis I spent in bed. Life went on like this for about six and one-half months. When I decided to have a transplant, I figured there was nothing to lose. Dialysis was always there to fall back on.

Betty Walker is an insulin-dependent diabetic who has had an active and productive life since her kidney transplant 9½ years ago.

So, on July 13, 1978, I was "born again." My mother, Fran Bator, gave me life when I was born and gave it to me again when she became my donor. The transplant was done at Yale-New Haven Hospital. It should be called a "transformation" because that is what it was for me.

I could hardly believe it, but the day after the transplant I wanted to eat. I was told that I had to wait another day. When the next day came, given jello and ginger ale, I told a doctor that I wanted "real" food. I ate like a horse the next day, devouring all the food on my tray. I also felt like running or doing something to release my energy. My hematocrit rose from 12 to 40. All of my blood chemistries were normal. The only problem was with my blood-sugar which had risen because of the steroid drug. This was taken care of by more insulin.

For me the most frustrating thing was that I could not take a shower or bath until the stitches were removed. Wouldn't you know it, they left them in for 16 days. As soon as the doctor removed the stiches and was out of the door, I was in the shower.

Since I became blind I have had a philosophy: I do not say something can't be done unless I try to do it first and know I can't do it. So far the only thing that I have found I can't do is drive a car.

I lead a fairly active life since my transplant. My favorite leisure activity is horseback riding. Yes, it can be done by a totally blind person. I also enjoy swimming, hiking, sailing, ice-skating, arts and crafts, cooking, baking and writing poetry. Included at the end is one of my poems, "Natural High," expressing my outlook on life.

In closing I would just like to say, "Never Give Up and Don't Let Anything Get You Down."

If anyone would like to write or call me, my address and phone number are: Betty Walker, 1826 Mississippi, Jefferson City, MO 65101. (314) 634-7969.

Natural High
Whenever I am feeling high,
I find it very hard to lie.
My face will have a big bright smile,
And when I talk; I talk a while.
My high is not from any drug;
I may be "up" just from a hug.
Its cause is just a love of life;
That I hold onto with great strife.

(Editor's Note: The above is a reprint from *Voice of Diabetic,* Vol. 1, No. 1, January-March, 1986. Betty has sent us the following up-date.)

My original article was written in February, 1980, for the "Danbury Hospital Dialysis Newsletter," to encourage dialysis patients to receive transplants.

I have now had my kidney transplant for nine and one-half years. I have had no major problems in those years and my blood chemistries continue right in the middle of the normal range. I continue to do all of the things that I enjoy and work actively in the National Federation of the Blind.

David Walker, of Michigan, and I were married in 1982 in Minneapolis, Minnesota, at our National Federation of the Blind Convention. Shortly after our marriage, a new job for Dave brought us to Jefferson City, Missouri, where we reside today.

In January, 1987, I was elected president of the local chapter of the National Federation of the Blind. I am now the second vice-president of the Diabetics Division of the NFB. I encourage anyone who is undecided about transplation to "go for it."

Research Highlights From ADA Annual Meeting: Kidney Disease

Two studies, at the Joslin Diabetes Center and at the University of Minnesota, suggest that genetic factors may play an important role in the development of diabetic kidney disease. Diabetic nephropathy is one of the most devastating of the complications of diabetes. According to the National Diabetes Data Group, one-third of people with IDDM and one-fifth of people with NIDDM have developed nephropathy after 15 years of diabetes, and renal disease accounts for nearly one-half of all deaths among people with IDDM over the age of 20.

A random sampling of patients at the Joslin Diabetes Center revealed that 83 percent of those with nephropathy had a parent with a history of hypertension. In contrast, according to investigator Dr. Andrzej S. Krolewski, only 45 percent of those without evidence of nephropathy reported such a family history.

Hypertension, which is present in almost all people who have nephropathy, is known to be associated with progession of kidney disease. This study suggests that genetic predisposition to hypertension also may be a contributing factor in the development of this complication of diabetes.

A genetic predisposition to kidney disease also was noted by researchers at the University of Minnesota. Their study examined diabetic brothers and sisters of two groups of patients — those who had had a kidney transplant because of diabetic nephropathy and those who had diabetes but no evidence or renal disease.

"We found that 85 percent of the siblings of the transplant patients had evidence of nephropathy, and 12 had already progressed to end-stage renal disease," said researcher Dr. Elizabeth Seaquist. "In contrast, only 18 percent of the siblings of the patients without nephropathy had developed this complication.

(Note: This is a segment of an article that appears in *Diabetes Dateline,* v.8, no.4, published by the U.S. Department of Health and Human Services.)

Pertinent Data

(From page 7.)

ing is up to 90% of the total cost.

I strongly urge anyone undergoing dialysis treatments to check into a kidney transplant and find out the facts. Ask your nephrologist questions and write down what he tells you. Pose questions to a qualified transplant surgeon and check with the centers that perform transplant surgery.

A kidney transplant is not for everyone, but it should be given strong consideration, especially by diabetics experiencing renal failure.

There are many good transplant locations in our country; investigate the different centers and round up all pertinent data. I and many others highly recommend the University of Minnesota for kidney transplants. They are pioneers in the field; they did the first transplant on a diabetic. The University of Minnesota has transplanted more kidneys for diabetics than any other location in the world. Its medical staff has "given the gift of life" to more people than anyone else.

Diabetes is the leading cause of new blindness in adults. This means, of course, that all transplant centers deal with many blind people. I am a blind person and one of the reasons i like the University of Minnesota Hospital is because the blind patient is treated as any other and is required, unless unable to do so, to handle his or her own medical treatment. The University of Minnesota has an excellent transplant book which gives all phases of kidney transplantation, and if you have a vision problem you are provided with cassette tapes. I don't know it these services are provided at all transplant locations, but it should be checked out. You can easily find out by asking questions. For information concerning the transplant program, call toll-free 1-800-328-5465.

If you must travel to a transplant location away from your home area and need financial assistance for the transportation expense, you can call toll free to the American Kidney Fund: 1-800-638-8299.

To continue living the diabetic with severe renal failure must choose between dialysis and kidney transplantation. This article was written to supply food for thought for those who must make this difficult choice.

We diabetics should be especially cognizant of the vital importance of kidney transplantation. We should have a positive philosophy and tell ourselves that we are survivors. We can all be survivors by taking care of our diabetes and closely adhering to our medical program, by getting plenty of exercise, and by checking into the possibility of having a kidney transplant. Think about it and SMILE, it's going to be a great year.

Management of the Diabetic Patient with Kidney Disease and Blindness

Dr. John Najarian, Chief of Surgery at the University of Minnesota Hospital, spoke to the NFB convention on Thursday, July 8, 1982, and was introduced by Karen Mayry, President of the NFB of South Dakota. She said: "Eileen O'Brien and I are both successful kidney transplant patients who have come to know Dr. Najarian very well. About a year or so ago we talked with each other about this. We wanted diabetics who did not already know about the good program at the University of Minnesota to learn about it. We wanted to offer a support group to diabetics who are having renal failure. During the past year, we have set up what we call the Network. Many diabetics have contacted us. We have talked with them by phone and corresponded with them. This morning the diabetics here at convention met, and we'd be happy to meet with others following the morning session.

"Dr. Najarian is one of the individuals who helped develop the kidney transplant. I have had my transplant for 10 years and am doing extremely well. Dr. Najarian asked me: 'Aren't you tired after this convention?' Of course, we're all tired, yes. But we'll worry about that when we get home. We now have the Network established and we're hoping to help all diabetics who have renal failure. As I present Dr. Najarian, I want you to know that he is a member of this organization and an Associate."

Dr. Najarian spoke as follows: "Karen is an inspiration to all of us at the University of Minnesota as are some 950 other diabetic patients we have transplanted over the past 20 years.

"I would like to talk with you a little about diabetes, about kidney transplantation, and a little about pancreas transplantation. Diabetes plays an important part in blindness. It is one of the major contributors to blindness in the United States today. The things that we know are that it's the second most common cause of blindness; and it's the leading cause of new cases of blindness in adults. Diabetics in general are 25 times more prone to become blind, 17 times more prone to have kidney disease, five times more prone than non-diabetics to get gangrene of their extremities, and twice as prone to have heart disease.

"When we first started transplanting kidneys in 1962, we began transplanting non-diabetics, people who had kidney failure for other reasons. In 1967 I wanted to know why diabetics were not being transplanted. There were two major reasons. One, the people who manage dialysis (the artificial kidney) were not interested in the diabetic because the results of treating diabetics were so poor. Because of this, the doctors doing transplantation were also fearful of transplanting diabetics. The diabetics have to be placed on cortisone (prednisone), and this would cause their blood sugar to get worse. As a result, it may make it more difficult to transplant such patients.

We did the first transplant in 1966 on a patient with diabetes, who at that time was partially blind. He had kidney failure. We went ahead with a kidney and a pancreas transplant in combination. At that time we felt you had to do both: replace the kidney because the kidney had failed because of the diabetes and then try to correct the diabetes by giving a new pancreas.

John Najarian, M.D., is Chief of Surgery at the University of Minnesota Hospital and a pioneer with organ transplantation.

This was an unfortunate philosophy at the time, because all of our first ten patients in whom we placed both a kidney and a pancreas at the same time eventually lost their lives, although for a short period of time both the kidneys and the pancreas did work.

In 1968 we said: If 50 percent of all diabetics living today are going to die of renal failure, let's just put in a kidney, and see if we can manage them in that way. We started doing kidney transplants in 1968. We have done them now for the past 19 years on diabetics. Although we are the largest kidney transplant program in the world, having done almost 2700 kidney transplants altogether, we are the leading transplant proponents of transplanting diabetics, having done 950 which represents a significant number of the diabetics ever transplanted. We think it's important! By continually reporting our results to medical meetings, we were able to shame our colleagues (if you will) into transplanting diabetics. I am proud to say now that most transplant centers in the United States will transplant diabetic patients today.

"If you do nothing but transplant the kidney in the diabetic patient who is dying because his kidneys have failed, that will save his life, but what about his eyesight? The most amazing thing has occurred. In the past 20 years in reviewing the eyesight of all our diabetic patients, 33 percent or one-third are blind when they come to us (totally blind), and the others have some degree of retinal problems and blindness. At the present time, of those with any sight whatsoever, we have been able to improve the sight in 17 percent. We have been able to stabilize the eyesight at whatever level they were when we saw them in 62 percent. Only 21 percent over the past 20 years have had further deterioration in their eyesight.

The reason for this is amazing. How does a kidney alone preserve failing eyesight in the diabetic? It has to do with why eyesight is lost if you're diabetic. During the last phases of kidney disease, you become hypertensive and get high blood pressure and have bleeding problems. With these two things, you eventually have a very rapid progression of loss of eyesight. If you can stop the uremia by putting in a new kidney and normalizing the diabetic, then you can stabilize the eyesight. This has gone on for 19 years in almost two-thirds of the patients we've transplanted. More amazing, how do you improve eyesight with simply a kidney transplant? We look at the patients that we've done. We have some excellent ophthalmologists that work with us. We have seen a decrease in the macular edema. This is the fluid around the area in which the eye is able to see. We have absorption of vitreous hemorrhage which is the major cause of the immediate blindness that the diabetic experiences. And we have been able to do vitrectomies, remove the vitreous humor within the eye where the hemorrhage was present to prevent further progression and improve eyesight. In some instances we did an operation on a cataract of patients with cataracts. Our friends in ophthalmology are of great help as all of you know. They're the ones who have shown the way along with us in not only looking at what's going on in the diabetic but all others with failing eyesight.

"I'll just mention a word or two about the kind of progress that's being made there. The laser has been one of the most remarkable things that the ophthalmologist can use for stopping the progression of sight loss, particularly in the diabetic. Some circumstances we know. When you have what we call proliferative disease (lots of extra blood vessels get in the back of the eye of the diabetic) we can destroy them with a laser beam. By destroying those, we can (in fact) then improve the eyesight or stabilize it so it doesn't go on to total blindness. In addition, with the laser we can take care of what we call macular edema. That's the area of your eye that sees. It gets too much water in it. The reason the water is there is because the capillaries are leaking in that area. With the use of the laser we can block those capillaries and slow down that problem.

In addition, a remarkable thing is a vitrectomy, the ability to remove the vitreous humor in the eye. We do this only when there is hemorrhage in the vitreous which does not absorb. Then it can be removed. In addition we have a thing called traction retinal detachment, when the retina is pulled away from the back of the globe of the eye. This can be prevented by use of vitrectomy. With all these things in mind and in our hands and with the increased technology that's going on now, the improved techniques in material we can use, vitrectomy and laser therapy have done a remarkable job in at least holding off progression of eyesight loss, and particularly in diabetic patients.

"I cannot overstress the importance of transplantation in those diabetics who need it to stop further progression of loss of eyesight. Remember, if you have any eyesight at all and you're diabetic and you get transplanted — two-thirds will stabilize that eyesight and approximately 20 percent more will actually have improvement. Therefore, I think this is something to consider very seriously.

"Let's think for a moment about diabetes a little bit differently. There's only one real way to cure diabetes. That's with the use of a pancreas transplant. The trouble with the diabetic is that his pancreas doesn't work. The islets of Langerhans (little areas within the pancreas that make insulin) do not work. They're destroyed. We think it's probably autoimmune in nature, but they're destroyed. If we can give a new pancreas, then in fact we can cure the diabetic patient.

We began, as I stated before, back in '67 with trying to give a pancreas and a kidney to the diabetic patient. It turned out to be too much of an operation for them. So we stopped

(Continued on page 12.)

Management of the Diabetic Patient

(From page 11.)

and did kidney transplants alone. But we didn't quit. We went back to the laboratory and we said: Maybe we can just take out the cells within the pancreas that make insulin, the islets themselves, and transpant those. Maybe that's enough. We tried that on over 20 patients. We could lower the amount of insulin they were taking, but we could never cure a single patient with that technique.

In 1978, then, we went back to looking at our old technique, but one that was perhaps a lesser technique of pancreas transplantation, that is to give just half the pancreas in transplantation, something we call segmental pancreas transplant. It provides two new opportunities. One, and foremost, you can use a living related donor. In other words, you could use a mother or father or brother or sister where you take half the pancreas and leave half with the original donor. That was one advantage. The other is that it's a much lesser operation than using the whole pancreas as we had before. It is less stressful on the diabetic, and perhaps there is more chance of success.

I'm happy to say that in the last nine years since we started this, we have done 200 pancreas transplants in diabetic patients, and a total of 180 patients. Ten of those patients received a second transplant because of rejection of the first. In those patients in every instance we've had function. We've been able to take the patients off insulin at least temporarily. Eventually, some of these pancreases have failed for a variety of reasons. They have failed because of rejection of the tissue itself which we couldn't stop with our current drugs or they failed because of technical reasons. There are things we have to learn about making this a better operation.

Today we have a better operation. Many of these patients are completely off insulin. For those of you who are diabetic, you know what that means. Sticking yourself once, twice, three times a day; being on an insulin pump; watching your diet; and all the rest that goes with it. To be able to throw that away in one fell swoop is amazing. We're getting there now. We're just beginning to get there now. Those of you who are not diabetics, it's easy to empathize with the diabetic and to realize what kind of problem that is. If you're not diabetic, think about it for a moment. You're now totally blind and you have to give yourself insulin. Think about what you have to do.

"What's going to happen in this area? Currently, our longest patient is nine and a half years. One of the first patients with a pancreas transplant has not taken a drop of insulin in nine years. She appeared in a journal called *Diabetes Forecast* about two years after her operation. When we first did her, she was legally blind. This meant that she had 20/200 vision in her best eye. Currently, she has 20/30 vision in her eyes. Interestingly enough, she is working in Pittsburgh for a transplant unit. She is doing social work and doing it very well. This is the kind of thing that can be achieved. Not only do the eyes get better, but the kidneys which have become worse with the diabetes also get better. The kidney function improves once the pancreas is corrected. These are good things that have come along.

"It would be remiss of me not to include one final thing that has come along with the diabetics. That is that, not only are pancreas transplants coming, but we are also developing artificial pancreases as well. These are instrument in which insulin can be delivered to the body without the injection process. They can be used as an insulin pump on the outside of the body with a needle placed in the abdomen or they can be implanted as pumps inside the body and injected and filled with insulin every two weeks or more or less, depending on how much insulin they're taking, and they continually work day and night. They're not ideal, but they're a lot better than sticking yourself with a needle. With better control (all diabetics can tell you) your chances of having complications will decrease remarkably. Control is necessary and if insulin pumps help provide that, then that's an extremely important advance as well. So there's hope.

There is the possiblity of pancreas transplants for those who need them, although that's generally not the first thing that's needed. Usually the first thing that occurs is a problem with the kidneys. The patients should either be on dialysis or they should be transplanted, and preferably transplanted. If the pancreas continues to come along as it is, then I think that's going to offer real hope. And the insulin pumps also offer hope.

"This is the message that I have for you today. I think it's an upbeat message. It's the first time we've had something really concrete to look at in an important or leading cause of blindness today, mainly diabetes mellitus."

There were a number of questions from the audience for Dr. Najarian. Eileen O'Brien asked him to comment on the use of dialysis versus the kidney transplant. This is what he said: "The question really is when a diabetic is in kidney failure should he go on dialysis, the artificial kidney treatment, or transplantation? Obviously, I am a transplant physician, and I would push that. There is no data at the present time to show that dialysis is any more than a holding pattern, and not a very good one for most diabetics. Diabetics are hard to dialyze, and the results at the end of a year or two will be worse than they are with transplantation by 10 to 15 percent.

More importantly, dialysis itself has an adverse effect on the eyes if there's still sight present. The patients on hemodialysis (that's where the blood vessels are used) have to be placed on blood thinners. Often this causes a problem with further hemorrhages in the eyes. In essence, if you have a choice, the choice should always be for transplantation. Even the best and most honest dialyzer will agree to that. If you don't have a choice then dialysis is second best."

Evelyn Salle asked if there is a limit to how old a person can be and still be eligible for a kidney transplant. Dr. Najarian answered: "Most of the transplants we do are in people under the age of 55. We've recently raised it to 60. You begin to get into too many problems with older patients when they're placed on the kind of drugs you have to place them on to keep a kidney or a pancreas in place. At the present time we've extended our horizons up to 60. They used to be 40. We're getting up there, but we're not yet talking about really the very elderly patient."

Connie Comorato asked about funding to pay for kidney transplants. Dr. Najarian answered: "I know of very few patient who have ever had to pay for the procedure. You can ask Karen and Eileen. At the present time, the cost of the operation for a kidney transplant is funded by the Social Security Administration. That funding is up to 90% of total. Anything above that is usually covered by third-party payments. I am really not aware of anybody that's had to pay for anything of any significance on a transplant."

Rick Plumstead asked about precautions to be taken in families where there is diabetes and about the expectations for inheritance of diabetes. Dr. Najarian answered: "It is hereditary, but the degree of inheritance is so poor that you can go for three or four generations and never see another diabetic. For the type of diabetes we're talking about, which is the juvenile onset diabetes, diabetes that occurs before the age of 40 or 45 years of age, I'm not talking about adult onset diabetes that occurs after the age of 45 which is a very mild form. It can often be treated by diet or taking pills. I am talking about juvenile onset diabetes. This is the bad one.

How often should your children be tested? Not more often than once a year. The only thing that needs to be tested really is the sugar in their urine. If you get concerned, you can always get their blood sugars done. The diabetes that has onset after 45 is definitely inherited. The juvenile onset is what we call low penetrance. It's so spotty you really don't know. If you have diabetes and your wife or spouse does not, and you had five or six children, all of them could be free of diabetes. After 45 if there is anybody that has adult diabetes, you are very prone to getting it, that's if there are members of your family who have it."

Frank Snee asked what to do when there is numbness in the hand because of fistula for dialysis in the arm. Dr. Najarian answered: "If your hand is numb and you are having difficulty with it, then they may consider closing that fistula and putting one in your other side. What happens with the diabetic is that the circulation is so poor that when we try to create a fistula (a communication between the artery and the vein) in order to do dialysis, we rob the blood from the distal part which would be the hand. That's the reason why your hand is numb. If this becomes a very severe problem for you, the fistula should be closed and another one created either in the other arm, or higher up in your arm."

Ruth Whelan asked how long a person could have diabetes and have a pancreas transplant attempted. Dr. Najarian answered: "I want to really stress this. When we're talking about a transplant today, we're not talking about all juvenile onset diabetics. The only ones that we're transplanting currently (and we've done 200 in nine years, not a huge number although one-quarter of those that have been done in the world) are those patients who previously had a kidney transplant and are already on immunosuppressive drugs. In isolated instances where we have patients who have rapidly progressive blindness or rapidly progressive renal disease secondary to their diabetes and do have a sibling (a brother or sister) who is well matched to them so the risk of the transplant would be minimum, then we're doing transplantation. This is not open to all patients at this time. It's still experimental. We're just beginning to feel our way."

Louis Anderson asked how long after the onset of diabetes should one expect to have kidney problems. Dr. Najarian answered: "In general we found it takes about 20 to 25 years before the diabetes affects the kidneys."

David Walker asked for further comments on the insulin pump and on follow-up with the surgeon who did the kidney transplant or a nephrologist. Dr. Najarian answered: "I didn't mean that the insulin pump should be for everybody. It is one of the new things on the horizon. I'm just telling you the new things coming along. Selected people who are using pumps are doing very well. It is excellent for those who can use it and do use it properly. As far as follow-up with patients is concerned, all of our patients are followed by both the surgeon who did the kidney transplant and the nephrologist."

Although others in the audience would have liked to ask questions, President Jernigan was forced to terminate discussion and move on to other items on the convention agenda.

(Statistics revised 1987.)

Ask Dr. James

by Ronald James, M.D.

For the past 37 years, Dr. Ronald James has been an insulin dependent Type I diabetic. He is now working with the Midwest Diabetes Treatment and Education Center in Columbia, Missouri, and is the medical director of the Central Missouri Diabetic Children's Camp Inc.

Please Note: If you have any questions for Dr. James please send them to the editor. The only questions Dr. James will be able to answer are the ones used in his column.

Question 1: At what age should a child begin giving his own injections?

Answer 1: The age at which a child should begin giving his own injections will vary from one child to another. On the average, most children are not capable of accepting responsibility for their injections until they are about twelve years of age. However, some children may actually be able to give the injections when they are no more than six years old. Of course at that age it will usually be necessary for the parents to draw up the insulin doses. At any age, the parents must know what the child is doing. They must see that the child is correctly loading the syringe and using proper technique when administering the insulin injection.

Ronald James, M.D., is a long-term diabetic of 37 years. He is now working with the Midwest Diabetes Treatment and Education Center in Columbia, Missouri, and is the medical director of the Central Missouri Diabetic Children's Camp, Inc.

Question 2: I have diabetic retinopathy and can't see my insulin syringe very well. Are there instruments on the market that I can purchase so that I can be independent and self-manage my disease?

Answer 2: There are several types of magnifying devices that can be used by the visually impaired that may, at least in some cases, make it possible for them to see the markings on the syringe and thus be able to fill their own syringes. Of course, good lighting is absolutely essential for anyone who has impaired vision. For those totally blind, there are several devices available that will either allow one to pull the syringe plunger back to a preset dose or allow one to draw up certain amounts of insulin by specific actions such as rotating the knob on the device a certain number of turns. One of the problems with these devices is that it is impossible for the blind diabetic to see air in the syringe. This may result in an error in the insulin dose. However, in many cases use of the devices may be the only possible way for the diabetic to be able to function independently.

More recently there has been marketed by Squibb-Nova, Inc. an insulin injection device called the Novo Pen. For those who take multiple injections of only regular insulin it can allow for independence. The insulin dose is determined by the number of pushes of a button on the end of the pen, one push representing two units of insulin.

It should be noted that the Diabetics Divsion of the National Federation of the Blind has a resource listing of items that blind or visually impaired diabetics can use to help them be independent and self-manage their disease.

Question 3: I have had two minor strokes due to diabetes. Is there anything I can do to prevent or minimize the chance of having future strokes?

Answer 3: Yes. We feel there are certain risk factors for strokes and anything one can do to decrease or minimize these risk factors might help to prevent future strokes. One should maintain good control of the diabetes, appropriately treat high blood pressure, stop smoking if one smokes, keep the serum cholesterol and triglycerides in the normal range, achieve and maintain normal weight, and observe other good health habits. In the case where there is a partial block of an artery leading to the head, removal of the block, usually by surgery, before the artery is totally occluded may prevent the development of further strokes. Also, the use of certain blood thinners such as aspirin and dipyridamole is advocated by many physicians to help prevent strokes.

Question 4: Can a disposable syringe be used more than one time?

Answer 4: Yes, they can. I believe that manufacturers of disposable syringes usually recommend they be disposed of after one use. However, most diabetics find they can be used multiple times. The question of sterility has been raised, but it is felt that if one uses appropriate technique, sterility should not be a problem. First, after use one should move the plunger back and forth to remove any insulin that may remain in the syringe. Secondly, the syringe should then be capped and placed in a refrigerator in an effort to keep down bacterial growth. Finally, one may wish to wipe off the needle with an alcohol sponge prior to filling the syringe each time. The limiting factors as to how many times one may use a disposable syringe are deterioration of the markings on the syringe and the needle becoming too dull.

Question 5: What is an insulin infusion and why are they so important during hospital procedures and operations?

Answer 5: An insulin infusion means that the insulin is placed in a container of I.V. fluids and runs directly into the vein. There are differences of opinion as to whether a continuous infusion is better than giving insulin directly into the vein as a bolus. Whether given by continuous infusion or bolus, intravenous insulin is a means whereby, during hospital procedures, the patient can continue to obtain insulin at times when it might not otherwise be well absorbed from under the skin, as for example during times of low blood pressure. Some prefer insulin infusions because the insulin can be placed in a container of glucose and thus the insulin will get in at a rate proportional to the rate at which the patient receives the glucose. Thus, insulin infusions may be useful during hospital procedures and operations.

Question 6: I am blind due to diabetic retinopathy and want to know it there's a possibility that I might get my eyesight back?

Answer 6: In most cases those who are totally blind due to diabetic retinopathy will not be able to regain useful vision. However, with modern technology, in some cases it is now possible for an ophthalmologist to remove blood and other materials from inside the eye, thus allowing the light to reach the retina, and when the retina is intact, allowing the diabetic to regain useful vision. This procedure, called pars plana vitrectomy, is being used more and more, and may be quite beneficial for many diabetics who have their vision impaired by diabetic retinopathy. You should discuss this with your ophthalmologist.

Question 7: Diabetic foods are terribly expensive. Why?

Answer 7: Diabetic and dietetic foods are terribly expensive principally because many people will pay the price. Our free enterprise system often allows as much profit as possible and this is one of the places it can sometimes be achieved. On the other hand, the wise diabetic should recognize that he does not need dietetic or diabetic foods but that he can use the usual foods with the exception of sweets that anyone else eats and still follow his diabetic diet. The diabetic diet need not be any more expensive than any other equally nutritious diet. In fact, how much it costs will basically depend on how "high on the hog" one lives, so to speak. For example steak, shrimp, and lobster can be used as meat exchanges. If cost is a consideration, eggs, cheese, hamburger, etc., which are much cheaper, can also be used providing equally good nutrition while perfectly compatible with the diabetic diet. Therefore, the cost of the diabetic's diet is a matter of education and selection and not a matter of high prices of foods labeled diabetic and/or dietetic.

Question 8: Are there any diabetic jellies or jams that I can have?

Answer 8: Yes, any type of jelly that does not contain any sugar or form of sugar. Words ending in "ose" or "cl" are words that are often other names for sugar. Sorbitol, mannitol, and zylitol are called sugar alcohols and are often found in diet jelly. Sugar alcohols are a form of sugar that can affect blood sugars. Other forms of sugars that many diet jellies contain are fructose, honey, corn syrup, and high fructose corn syrup. Examples of brands of jelly on the market that contain no form of sugar and can be used by the diabetic are Dia-mel and some of the Featherweight jellies.

Question 9: If a needle is broken during injection, what should I do?

Answer 9: The broken needle should be removed if possible. If it can be found grasp it with the fingers or tweezers and remove it. If this can not be done one should see his physician. In some cases it may be quite difficult to find a small needle under the skin. A scar will be formed around it and it may be preferable to leave it there for the rest of the person's life. On the other hand, the needle site may become infected. If that happens the location of the needle will become evident and it can be removed by a physician.

My Kidney Transplant

by Ed Bryant

Ed Bryant has had diabetes for 29 years and had a successful kidney transplant 4½ years ago. "Life is certainly better after having a kidney transplant."

My cross to bear in life is diabetes. I found out how insidious and wicked the disease can be in 1978 when my physician told me that I was undergoing renal failure and that when my kidneys finally could no longer filter wastes from my system, I would have to go on dialysis.

A normal vein cannot tolerate the 16-gauge needles that are inserted into the arm during hemodialysis. So my doctor surgically connected one of the veins in my wrist with an artery, thereby forming a fistula to better accommodate the large needles for dialysis.

In December of 1979, I began dialysis. My treatments were three times weekly and each lasted about four hours. I continued to dialyze for 3½ years. During that time, I traveled quite a bit and dialyzed at other centers. I found that many dialysis patients feel nauseated and weak after treatments and require the remainder of the day to regain their strength.

I was a lucky diabetic at first. I usually felt great after dialyzing and, unlike many, could continue my normal daily activities. Most dialysis patients find that if they follow the strict limitations for liquid intake and watch what they eat, they can do pretty well on the treatments.

About 30% of those on dialysis are diabetic. Long-term diabetics, in most cases, have cardiovascular and blood pressure problems, and the added strain of dialysis often is too much for their bodies to withstand. While I was on dialysis, four of my diabetic friends on dialysis died due to this added strain.

After about three years on dialysis my luck started to run out; I began to feel ill. I lost weight and had a constant pale look. I did not know if I was getting ready die, but I did know I was not doing well at all.

In 1982, I attended a national convention of the National Federation of the Blind where I heard a presentation by Dr. John Najarian, Chief of Surgery at the University of Minnesota Hosptial in Minneapolis. He covered the topic of kidney transplantation in diabetic patients. After hearing Dr. Najarian's speech, I knew I needed more information on kidney transplants before considering it as an alternative to the dialysis treatments which were causing my health to fail.

Research pointed me toward a kidney transplant. I found the life expectany of diabetic transplant recipients to be considerably longer than that of dialysis patients. Although some people may not qualify for a transplant because of their age or physical condition, my doctor considered me an ideal subject. After weighing the evidence against the odds, I decided to "go for it" and chose the University of Minnesota Hospital for the surgery.

My sister, Debbie, was to donate one of her kidneys to me. I will be eternally grateful for this generous act of love. It is a wonderful gift and my feelings for this act are indescribable.

The first step was to start taking the immunosuppressive drug azathioprine, which would protect my new kidney against my body's efforts to reject it. However, on the day I checked into the hospital to prepare for the transplant, the doctors found the the drug had caused my white blood cell count to fall dangerously low. The surgery had to be postponed until my body could replenish my white blood cells. I left the hospital and discontinued my use of azathioprine.

While waiting for my white blood cell count to rise, I learned about a new immunosuppressive drug called Sandimmune (cyclosporine). The Food and Drug Administration had not officially approved cyclosporine, but it was being tested at chosen transplant centers and the results to that point had been extremely positive. The kidney survival rate for those using cyclosporine greatly exceeded that of any other drug of its type.

Two months later, in August of 1983, my white blood cell count finally returned to a normal level. I returned to the transplant center and I asked the doctors if I could be a "guinea pig" in the cyclosporine tests. The surgeons told me I could, and they foresaw no problems with the revolutionary new drug.

New kidneys, like mine, are placed in the lower abdomen where they are best protected. Kidney recipients receive only one kidney, which is all that is needed to handle all body functions. A new transplanted kidney will grow or diminish in size to best serve the body in which it is placed.

After the surgery and eight days in the hospital, I began a healthy life with my new kidney. I exercised daily and felt like a million dollars. I no longer felt tired or drained as I had when I was on dialysis. I woke up each morning feeling energetic and ready to handle a busy schedule.

Many people think that major surgery is risky or that they may lose their lives. In reality, there are high numbers of diabetics who die each year when they could have greatly improved their quality of life and increased their life expectancy by transplant surgery.

I strongly endorse kidney transplantation. I am a living example of the improved "quality of life" after a transplant. I say "Go for it!" At least give it strong consideration. Check out the possibility thoroughly and get answers for all of your questions before you make a decision. Your quality of life and, in fact, your life may hang in the balance. Ask your nephrologist for more advice and information.

I hope that my experiences will provide you with food for thought. If you have any questions please feel free to contact me.

Kidney Patients Have Few Choices in Combating Disease

(**Editor's Note:** We are reproducing some sections of a much longer article by Paul Recer (AP) which appeared in the Rapid City, SD, *Journal,* Sunday, May 8, 1983, p.41, to show that occassionally dreams are surpassed by reality. Today, due to cyclosporine, kidney transplant success rates are better than those predicted in 1983.)

Of all the catastrophic illnesses, few slice as deeply into the life of a victim as kidney failure. Most medical experts believe it is personally more devastating than cancer, heart disease, or stroke.

Children with kidney disease stop growing. Adults experience sexual dysfuntion. Victims often lose their jobs, their spouses, their friends, their independence, their savings. Their very existence revolves around a machine.

Severe depression is common. Worst of all, perhaps, is that there is no end in sight.

"With cancer," said Dr. Rege Stewart, a Dallas psychiatrist, "you have a deadline and the odds of survival and, perhaps, a remission.

"But a kidney patient may be in dialysis for a year or 15 years or forever. There's no light at the end of the tunnel. There is the uncertainty of a conclusion. This makes it more painful for the patient and the family than does cancer.

Some argue that 'marginal patients' — the elderly, the diabetic, the persons with other critical illnesses — shouldn't receive dialysis anyway.

"Some doctors take a stand, refuse to give dialysis and let nature take its course," said one physician at the National Institute of Health who declined to be identified. "Others get intimidated by the family or the threat of a legal action and order dialysis even though the patient will never be able to function normally."

A new drug, now being tested, may change the kidney transplant picture completely.

The drug is called cyclosporine and its advocates call it the most important advance in immunosuppression therapy.

Cyclosporine, which was previously known as cyclosporin A, has been used in successful heart and liver transplants and in scores of kidney grafts. Among doctors who have used it, the drug is highly praised.

Dr. Thomas Starzl, a University of Pittsburgh surgeon and transplant pioneer who has used cyclosporine in liver transplants, predicts a revolution in treatment.

Starzl said the drug could provide a significant savings to taxpayers, "who pay the $2 billion a year End Stage Renal Disease program (costs)."

Starzl predicted that cyclosporine could increase the success rate for transplants using cadaveric kidneys from 50 percent to 80 percent.

For now some kidney specialists are not enthusiastic about transplantation.

Other doctors have hinted at darker motives by the nephrologists. Many dialysis center are partly owned by nephrologists, some of whom have been accused of resisting transplant surgery because they would lose money if patients were cured by transplants.

In most cases, (Dr. August R.) Remmers said, nephrologists resist transplantation because of the risks. They are not yet sure that cyclosporine and other new drugs offer the promise that Starzl predicts.

"We don't really know yet if they are right," Remmers said. "I hope they are."

Until the success of cyclosporine is proven, transplantation will be chosen by the very few — the young, the courageous, those who feel the risks are worth the chance.

For the rest of the nation's kidney patients, most will continue going thrice weekly to the dialysis center, with 80 percent of the bill paid by the taxpayers.

Dialysis, they believe, is safe and sure and, after all, the government pays for it. Many feel they must go to the centers, because, as one said, "otherwise you die."

A Donor's Side

by Debbie Dupree

Debbie Dupree donated a kidney to her brother Ed Bryant 4½ years ago. She tells of her positive experiences of giving the gift of life by donating an organ.

After three years on dialysis, my brother Ed needed a kidney; so our entire family sent the needed blood for testing to the University of Minnesota, where the operation would take place if they could find a compatible donor. Our parents were ruled out because of age, so it was narrowed down to my second brother, Jim or myself.

Ed's doctor called me at my office to tell me that I had been chosen. My blood tissue was a good match with Ed's and if I were willing to be the donor, Ed would not have to undergo the removal of his spleen prior to the transplantation. **(Editor's Note:** Splenectomies are no longer needed for transplantation.) I told Ed's doctor that he could count on me.

A battery of tests was needed to determine my good health and the compatibility of our kidneys. Our kidney match turned out to be 4-0 — a perfect match! The University of Missouri Hospital did the pre-testing. They were very cooperative, working with and around my own work schedule. Since my sick leave was limited, I had the testing done as an out-patient.

I was fortunate that my work was within walking distance from the clinic and lab and that my supervisor at work was extremely understanding and cooperative. I'd like to say here how much I appreciate the thoughtfulness and consideration my employers showed me at that time. I worked with the State of Missouri in the department of Mental Health, and everyone was concerned about me and worked with me to make the organ transplant possible. They helped me acquire the necessary leave time and were a great support for me.

The tests consisted mostly of bloodwork, urine tests, and a few x-rays. They were not complicated or painful; no more than a few pricks. The time involved as an out-patient was about 12 to 16 hours. My husband's employers were also considerate and understanding. They allowed him to take as much time off as was necessary.

In May 1983, the time finally came for us to make the 500-mile trip to Minnesota. We were impressed when we got there. Minneapolis-St. Paul are beautiful cities, and the University Hospital is huge, but the staff was warm and friendly. They did everything they could to make us comfortable.

All of my test results had been sent to Minneapolis, but there was one more test needed — the angiogram to determine which of my kidneys they would use. I must say this was the most painful test of them all. But, praise the Lord, it didn't last long.

Finally it was discovered that Ed's white blood count was too low for surgery, and I was released from the hospital. We all returned home to wait. It seemed like a long wait because I had been ready and anxious to get the transplant over. It must have seemed even longer for my brother.

Three months later, in August, we were ready to go again. This time my son, who was 10 years old at the time, was out of school and went with us. My daugher, seven, stayed with her granddad while we were gone.

We were admitted into the University of Minnesota Transplant Center, and the routine preparation was done. I felt very relieved that everything was ready and that the next morning would be the big day. It's difficult to express how I felt the night before surgery. I don't like being in hospitals, and the idea of being cut on didn't thrill me. I thought of my brother — it would be harder for him because he was not healthy. I had concerns about the success of the transplant, and I worried about how my brother would feel if the kidney didn't "take." But, success or failure, Ed deserved the chance. I had faith that God was with us in this, and that He was in control. My family, friends, and many church congregations had been praying and continued to pray in agreement for the complete success of the transplant and for God's peace to be with us. That night I felt the actually being under anesthesia and peace of God and was ready for the next day.

We were in surgery for 4-5 hours. I don't remember much of that first day except waking now and then and seeing that my family was there. As I gained consciousness, I felt the pain from the incision and the muscles around it. I discovered muscles I'd never before been aware of. It was agony to move and especially to cough or sneeze.

The doctor had told me I'd be in the hospital seven to 10 days after the surgery, but I recovered quickly and was released after only four days.

The drive home from Minnesota stands out in my memory as one of the roughest parts of the entire ordeal. I had four pillows surrounding me in the car to help cushion me from the bumps and jolts. But it was an exhausting trip to say the least.

I felt like an invalid for the first week at home. I couldn't lift over 10 pounds, I could barely get out of a chair by myself, and I couldn't get out of bed by myself. Our waterbed created quite a problem. Since there is nothing solid on a waterbed to push or pull on, I found myself marooned in bed more than once. One time I was stuck in bed half a day until someone came home and rescued me!

Gradually, faster than I had expected, I was able to get around and do for myself. I could have gone back to work four weeks after the transplant but didn't until after six weeks, at which time the only physical evidence of the transplant was a numbness around the incision site. Now, after about four and one-half years, there is still a slight numbness around the scar, but this causes no discomfort.

If you are in need of a kidney and there is a possibility to receive one from a living related donor, don't be afraid to ask; if you are related to someone in need of a kidney and you have two healthy ones of your own, don't be afraid to offer this gift of life. It is not traumatic. The time and discomfort involved are minimal compared to the physical and spiritual lift experienced by donor and donee.

I honestly do not miss the kidney I gave away. Neither my life nor my health has been changed, but my brother's have. Because of a kidney that I didn't need and don't miss, he is a productive person again.

Postscript from Ed Bryant:

I have felt great ever since having a kidney transplant. I would be remiss if I did not use this opportunity to say I will be eternally grateful to my sister. I simply want to convey the feeling of love I have for her. I strongly recommend all people with renal failure to consider a kidney transplant. The National Kidney Foundation is correct when they say the kidney is the "Gift of Life."

As Debbie has already stated, neither her life nor her health has changed since her generous gift to me, except that on March 3, 1986, she gave birth to Daniela Anne Dupree, a beautiful, healthy baby, 20 inches long and weighing in at six lbs, 14 ozs.

Kim Cleeton had a pancreas/kidney transplant three years ago. She works and leads a constructive life.

Once a Diabetic Always a Diabetic?

by Kim Cleeton

Once a diabetic, always a diabetic? This is not true in my case, although diabetes has done its damage to my body. I have been one of the lucky ones to have received pancreas and kidney transplants, a little over three years ago. I *no longer* take insulin shots, omit sugars from my diet, administer dialysis or feel worthless and run-down. I feel great!

At the age of six I developed diabetes. Throughout my adolescent years, for convenience's sake I was not in good control of monitoring my diabetes. I am now 31 years old and I am a speech therapist in the public school system.

In 1979, I nearly went blind because of detached retinas in both eyes. I had been going to a local eye doctor but I should have continued with an ophthalmologist from the city. I did not do so, again because of convenience —a poor excuse! I was fortunate to get to an eye specialist to save my sight. I

(Continued on page 18.)

Towards Independence:
An alternative technique for drawing up Sandimmune (cyclosporine)

by Ed Bryant

Sandimmune is an immunosuppressant drug commonly used in conjunction with organ transplant operations to prevent the immune system from rejecting the transplanted organ. Historically, throughout the medical profession, there has been a pervasive conviction that blind transplant recipients cannot safely or accurately draw up their own cyclosporine unaided by a sighted person.

The following article postulates a procedure which will allow virtually any blind person to draw up his or her own Sandimmune while still fulfilling the all-important dual-criteria of accuracy and safety.

This procedure is not experimental. I am a blind kidney transplant patient and I have used it personally for almost four and one-half years and have yet to encounter any problems. My hope is that through this procedure, many blind people may be allowed to become less dependent on others in this significant aspect of their lives.

Additionally, I would like to encourage the various professionals within the medical community who deal with blind patients to whom this Ideal would be applicable to inform them of it. Such a self-help policy for blind people is in both the best interest of society, since it allows us, the blind, more of a sense of independence and dignity, and of the medical profession since it would free up medical resources such as visiting nurses for use in more pressing medical problems.

How to Make a Sandimmune Measuring Device (Stopper)

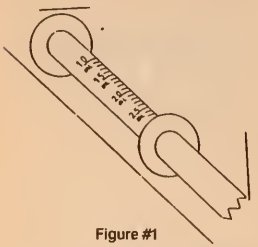


Figure #1

The syringe will hold 4 ml (or 400 mg). Markings are shown for milliliters 1, 2, 3 & 4. Each ml is further sub-divided into 10 equal parts. Thus each subdivision indicates .1 ml (or 10 mg).

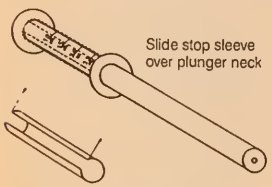


Figure #2

The completed measuring device (stop sleeve).

Materials required:

Two syringes for measuring Sandimmune, one single-edge razor blade, and one ruler.

Procedure:

1. Remove the plunger from one of the syringes. Set this plunger aside, you will not need it.
2. Raise the plunger on the other syringe until it reads the proper dosage required for the patients (i.e., I ml or 100 mg, 200 mg, etc.).
3. Measure the distance on this plunger between the finger tabs on the tube and the finger tabs on the plunger for the proper dosage.
4. Take the empty round sleeve on the other syringe and cut off a section of the tube which is a little longer than what you measured. (If you have only a 1-ml (100-mg) dosage, you cut two or three tubes from this sleeve.)
5. Hold one of the tube sections firmly and split the tube open length-wise by cutting from one rim to the other. This is like splitting a soda straw down one edge.
6. Again, holding the same tube section firmly, from one of the split edges shave off an 1/8" segment. The segment removed will look like a small curved rectangle about 1/8"-3/16" wide and the same length as the tube.
7. The stop sleeve now looks like the letter "C" and the open side will slip over the plunger on the syringe when the plunger is lifted.
8. Slip the stop sleeve onto the plunger neck and press the plunger down firmly. Because we cut the stop sleeve a little too long, we now need to trim the ends to make them neat and the proper length for the correct dosage. Note: The hard plastic may be sanded or filed for this purpose.
9. Slip the stop sleeve back onto the plunger to insure that it is the proper length.
10. This stop sleeve is your measuring device. You should cut a second one in case the first is misplaced.

How to Measure Sandimmune and Use Stopper

1. The bottle of Sandimmune should be sitting on a flat surface such as a table.
2. Insert the Sandimmune syringe into the bottle. Make sure that the plunger is pushed all the way in.
3. With one hand, hold the bottle containing the Sandimmune and the syringe, and with the other hand slowly pull the plunger out until you have drawn a bit more Sandimmune than the dosage calls for.
4. Insert the stop sleeve onto the plunger neck.
5. Push the stop sleeve in until the thumb pad is firmly against the stop sleeve. Note: Always continue to hold the bottle with one hand as it might otherwise tip over.
6. Remove the syringe from the Sandimmune bottle and remove the stop sleeve from the plunger. You now have the correct Sandimmune dosage in your syringe and are ready to mix it with whatever liquid you use.
7. After use, dry the outside of the pipette with a clean towel and replace it in the protective cover. To avoid clouding, do not rinse the syringe with water or other cleaning agents.

To determine how long a bottle of Sandimmune will last, simply divide the Sandimmune dosage (milliliters or milligrams) that you use each day into the total dosage contained in the bottle (i.e., if you use 2 ml each day, then the bottle would last 25 days or, if you use the equivalent amount of 200 mg each day, the bottle would last 25 days). There are 50 ml or 5,000 mg in each bottle. When the bottle gets close to being out of Sandimmune it is sometimes difficult to accurately draw the correct amount. To insure that the correct amount is drawn and as a safeguard, I assume that each Sandimmune bottle contains only 45 ml (4,500 mg) rather then the actual 50 ml (5,000 mg).

After using the 45 ml (or 4,500 mg) I open a new bottle and after using the same amount from the new bottle, I combine the contents of both the old and new bottles with the help of a small funnel.

It is easy to tell by the weight of the bottle when the amount of Sandimmune remaining is getting low. This same information can also be obtained by gently shaking the contents (be sure to replace the cap securely first!). Note: If you are ever uncertain about the dosage that you have drawn, do not take it!

Since the daily Sandimmune dosage usually diminishes with time after the transplant, you will need to modify the length of the stopper accordingly each time the dosage decreases. This can be done most easily by utilizing a file and/or sandpaper.

You will find that this device is extremely durable and has an almost indefinite lifespan. I have been using the same piece of tubing for almost four and one-half years.

A note to medical professionals: We certainly hope that you will pass along this helpful technique to any of your blind patients to whose circumstances it would be applicable. They will appreciate you for it.

A note to patients and consumers: We hope that you will pass along your knowledge of this procedure to physicians, nurses, and transplant units to enable them to serve you and others more effectively in the future.

All transplant units should show this method of measuring Sandimmune to blind people. Unfortunately, many people are not aware that blind people are quite adept at handling such a simple task.

The National Federation of the Blind exists to serve all blind people, to eliminate the myth that blindness is synonymous with inability, to accentuate the positive assets and abilities of blind people and to encourage these people to use these assets and abilites to their fullest. I'm on the board of the Diabetics Division of the National Federation of the Blind and serve as editor for our newsletter, *Voice of the Diabetic*, where my article and procedure were first published. For additional information, contact: Ed Bryant, 811 Cherry St., Suite 306, Columbia, MO 65201, Office Phone: (314) 875-8911, Home Phone:(314) 445-1928.

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(Editor's Note: In correspondence received by the editor, Lois Bartell, RN, BSN, said in part, "I plan to put the entire procedure as an integral part of the Handbook for Transplant Patients which is received by every transplant patient at the University." However, she prefers the use of scissors to the single-edge razor blade and states, "It works very well," The following is an endorsement by Lois.)

To all transplant patients:

At the University of Minnesota, we have been using the plastic sleeve measuring device (stop-sleeve) for the past year. Our former measuring device consisted of taping together a section of staples of the appropriate length. We find that the plastic sleeve is more durable and can be washed periodically. We appreciate the development of this concept as it is another way to promote independence among our vision impaired transplant population. We have always provided a means for labeling bottles and medicine cards to provide accurate medication preparation, but when it came to liquids our only device was a sleeve made from staples. Thanks to Ed Bryant and his creativity we now can make a measuring sleeve easier and more durable. I encourage its use by all patients.

— Lois Bartell, RN, BSN,
Organ Transplant Clinical Nurse Specialist, University of Minnesota Hospital & Clinic

Diabetes and Kidney Disease

National Kidney Foundation

What Is Diabetes?

Diabetes mellitus, simply called diabetes, is a disease caused by not enough insulin in the body or the body's inability to use normal amounts of insulin properly. This insulin imbalance causes a high blood sugar, and eventually many unhealthy changes can occur in different body organs.

Are There Different Types of Diabetes?

Yes, there are several types of diabetes, the most common ones being Type 1 and Type 2. Type 1 diabetes occurs mainly in young people, and is also known as "juvenile-onset" diabetes. It is caused by an inability of the pancreas to produce enough insulin. In Type I diabetes, the patient is dependent on insulin injections. Type 2 diabetes develops in people usually older than forty, and is also known as "adult-onset" diabetes. Close to normal amounts of insulin are produced by the pancreas, but the body is unable to respond to use it properly. The abnormal blood sugar can usually be controlled with a restricted diet and/or taking oral medication.

How Does Diabetes Affect the Kidneys?

As a result of diabetes, the small blood vessels throughout the body are damaged and the kidney as well as many other organs including the eyes, skin, nerves, muscles, gut and the heart are affected. Damaged blood vessels make the kidney less able to filter the blood properly. The elimination of excess salt and water from the body is reduced and toxic substances build up in the blood. Kidney failure resulting from diabetes is called "diabetic nephropathy."

If the nerves in the body are damaged by diabetes (called neuropathy), it can lead to difficulty emptying the bladder. Urine can remain in the bladder and the pressure that develops can back up and damage the kidneys. Also, if urine stays in the bladder for a long time infection may develop because of the rapid growth of bacteria in urine with a high sugar content.

Can There be Other Complications from Diabetes?

Patients with diabetes can develop high blood pressure (hypertension). There can be rapid development of hardening of the arteries (arteriosclerosis) and this can lead to heart disease. The eyes can be affected (called retinopathy) and the eventual outcome can be blindness.

What Else can Affect the Patient with Diabetes?

Diabetic patients are very susceptible to the adverse effects of certain pain medication. When taken by the diabetic, a complication from these medications can be a rapid loss of kidney function. "Over the counter" medications which contain *ibuprofen* can be very dangerous for the diabetic patient. The doctor should be consulted before the diabetic takes any medication.

What are the Chances of a Diabetic Patient Developing Kidney Disease?

Approximately 50% of Type I (juvenile-onset) and 10% of Type 2 (adult-onset) diabetics will eventually develop progressive renal disease which will lead to permanent kidney failure.

What are the Early Signs of Kidney Disease In Diabetics?

An early sign of diabetic kidney disease is protein in the urine, and this usually occurs after 10 years or more in Type 1 diabetics and occurs later in Type 2 diabetics. As the amount of protein in the urine increases, the content of protein in the blood decreases. A low blood protein content results in fluid retention which causes swelling in the legs, and increased urination at night. High blood pressure can develop or worsen as the disease progresses. Diabetics should have their blood, urine, and blood pressure checked regularly by their doctor. This will lead to better control of the disease and early treatment of high blood pressure if present.

TABLE 1
Early and Late Signs of Kidney Disease In Diabetes

1. *Protein in the urine*
2. *High blood pressure*
3. *Leg swelling, leg cramps*
4. *Night urination*
5. *Abnormal blood tests (BUN, creatinine)*
6. *Less need for insulin or anti-diabetic pills (oral agent)*
7. *Morning sickness, nausea, and vomiting*
8. *Weakness pallor and anemia*
9. *Itching*

What are the Late Signs of Kidney Disease in Diabetics?

As kidney function declines (as indicated by a rise in BUN and creatinine blood tests), non-specific symptoms can develop. These symptoms can be nausea, vomiting, loss of appetite, weakness, easy fatigue, itching, muscle cramps, progressive leg cramps, and anemia. The need for insulin may actually decrease because there is a breakdown of insulin by the diseased kidney. If any of these symptoms develop the patient should consult a doctor.

What can be done to Prevent Kidney Damage by Diabetes?

It is reasonable to expect that good control of diabetes can result in lowering the chance of developing severe kidney disease. It is extremely important to control high blood pressure as carefully as possible because hypertension aggravates any damage to the kidneys caused by diabetes. Getting adequate sleep, following the proper diet, avoiding cigarettes and alcohol, and getting regular exercise are healthy lifestyle habits that will benefit the diabetic patient. The patient should see his/her doctor on a regular basis.

It is important to remember that many patients with diabetes do not develop kidney disease and having diabetes does not necessarily mean that the kidneys are going to fail. A patient should discuss his/her particular case with a doctor to understand all the risks involved.

If Diabetes has Affected the Kidneys, What can be done?

If a diabetic develops any of the signs of kidney disease described above or is uncertain if kidney damage has occurred from the disease, the patient should ask his/her doctor. With blood and urine tests the doctor can tell whether the kidneys are functioning properly, and this will allow the doctor to prescribe the best treatment for the patient.

What will Happen If the Patient has Decreased Kidney Function?

The first step is to determine whether diabetes is the cause of the kidney problem. Other causes of kidney disease which can be treated will also be looked for. Adequate control of diabetes and blood pressure, treatment of urinary tract infections, correction of abnormal bladder function or urinary tract obstruction, and avoidance of medication that may damage the kidneys are things that can be done to help the kidneys work better and last longer. If no other problems are found, the treatment is aimed at slowing the progression of kidney failure.

How is the Progression of Kidney Disease Slowed?

The kidney specialist (nephrologist) together with the patient and family will plan the best individualized treatment. In general, controlling the blood pressure with medication and diet therapy appears to prolong useful kidney function and slow the progression to end stage renal failure.

What Is End Stage Renal Failure In Diabetes?

End stage renal failure refers to the time when the kidneys are no longer able to support a person in a reasonable state of well-being and dialysis and/or transplantion are needed. This period is usually reached when the remaining kidney function is less than 10%. The average time between onset of diabetic kidney damage and end stage kidney failure is about five-seven years, but it varies from person to person.

How is End Stage Renal Failure Treated In Diabetes?

There are three types of treatment that can be used once the kidneys have failed: kidney transplantation, hemodialysis and peritoneal dialysis. The type of treatment chosen will be determined by the general health and medical condition of the patient, by its impact on lifestyle and by personal preference. The overall success rate of each treatment type is of equal importance in this planning. Decisions regarding these treatments are individual and not final or exclusive. Many patients have received each one of these three forms of treament at various times. What may be the best treatment for one patient at one time may not be the best for another or for the same patient at a different time. The patient's doctor and other health professionals involved in the patient's care will discuss these different treatments with the patient and answer questions.

Can a Patient with Diabetes have a Kidney Transplant?

Yes, a kidney transplant can come from a relative (living related transplant) or a deceased person (cadaver transplant). After transplantation, the amount of insulin required for control of blood sugar usually increases because of better appetite and food intake, greater breakdown of insulin by the kidney, and the use of steroids to prevent rejection of the new kidney. If the transplanted kidney fails, dialysis treatment can be initiated and the patient can await a second transplant.

What is Involved with Hemodialysis for the Diabetic?

Hemodialysis is the most common form of treatment for end stage renal failure. A surgical procedure is performed to connect an artery to a vein (or artificial substitute if no veins are suitable) in order to create a large "arterialized vein" (fistula). Inserting

(Continued on page 18.)

Once A Diabetic

(From page 15.)

have had three vitrectomies and several laser treatments. My eyes are now stabilized and I am able to drive a car, although I am getting more nearsighted.

In 1981, my kidneys failed and I decided to go on continuous ambulatory peritoneal dialysis (CAPD). I chose this method because, by administering it myself, I could continue teaching. It was not an easy road to follow, but, believe it or not, I have forgotten a lot of the pain and tears. I lived one day at a time, but that's all anyone can do, right?

I was put on the kidney transplant list in 1981 at the University of Iowa Hosptial in Iowa City, Iowa, and was the 13th person to receive a double transplant there. I chose Iowa because their success rates were higher than other transplant centers.

I answered a couple of calls for a kidney, but in one case the final blood work did not match, and another time I had a severe cough. A year before I received my transplants, the hospital asked if I would be interested in a pancreas transplant if one was available with a kidney. Of course, I said yes. What would I have to lose for trying?

Things were not looking too good for me. I had previously been in the hospital receiving blood transfusions and trying to hold on. I finally received my call on Nov. 6, 1984 (Election Day eve). My immediate response was to cry. You're happy to think that this could be your way out of feeling so bad, yet you are so afraid of not knowing what the future holds for you.

After arriving at the hospital they did more blood matching and prepared me for surgery. Kidneys can be transplanted up to 72 hours after being removed from the donor, but a pancreas must be transplanted within four hours. I did not do a lot of reading about double transplants, because I am one to worry about what can happen. If I don't know about it, then I don't have to put myself through that emotional strain.

The kidney was placed in the right side of my abdomen and the pancreas in the left side. They began working from the very start. I probably watched my blood levels each day too closely because I worried about every little blood level that raised or lowered too much.

There were some complications: I developed an abscess around the pancreas and had to have two more surgeries. The incision had to heal from the inside out. It had to be cleaned and packed many times a day for several weeks after I came home. I was in the hospital for almost two months and went back to work in February.

What seemed really strange was the diet. It was a salt-free diet, but there were real desserts. At first the liquid diet consisted of sugar — popsicles, jello, hard candy, and juices. *Yuk!* All I wanted was broth or crackers. Believe me, you slowly but surely get used to having those desserts. My favorites were carrot cake and cheesecake. I now think I need something sweet after every meal.

After being released from the hospital, my blood levels still had to be watched closely. Some of the monitoring could be done at my local hospital and eventually my trips to the transplant clinic became fewer. I now go back to the transplant clinic every six months, and to my local hospital once or twice in between, for blood work.

As a transplant patient there are certain signs you watch for. You watch for weight gain of more than 2-2½ lbs. a day, elevated blood sugars, pain in the abdomen, or an elevated temperature.

The doctors and nurses tell me I am on a very small dose of medication. I take cyclosporine twice a day, prednisone, water pills, Imuran, and a vitamin. I am supposed to watch my salt intake; I do not salt at the table, but I do eat some foods with salt. I don't really feel I have any limitations, except to avoid hard blows to the abdomen.

When I first came home, I would eat something sweet and then take my blood sugar to see how the pancreas worked. I still do that at times. I am supposed to check my blood sugar frequently now.

I have to admit, if I had to lose one of these organs I would choose to lose the pancreas, because you can control the diabetes to an extent. But, when the kidneys go you have no energy and they control so many functions of the body. You can actually feel your life slipping away.

I am so thankful to have received both organs, and especially thankful to the family who donated them. The thought of an organ transplant puts such a mental and physical strain on an individual and his family that you wonder how you can make it.

I feel that along with the body accepting the organs, a positive mental attitude is an equally important factor. I could never have made it without the support of my family and friends. My mother was my backbone through the whole ordeal. She and my sister have always been there for me.

I have no idea how long these organs may last. They may stop tomorrow, in two years, five years, ten years, or who knows? I feel you should make the most of each day and be thankful for what you have. No one knows how long they will live. Even the most healthy person could walk across the street and get hit by a car.

You may develop eye, heart, kidney, or circulation problems. So, take care of yourself, control your diabetes, and do what your doctor says. Diabetic research has come a long way and great things are now happening!

Diabetes and Kidney Disease

(From page 17.)

needles in the fistula allows the patient to be connected to the artificial kidney machine. This machine cleans the blood and removes waste products that build up in the body. The treatments last three-five hours and usually need to be performed three times a week. This type of dialysis can be done in a hospital setting, outpatient dialysis clinic or at home (after training).

Can the Patient with Diabetes be Treated with Peritoneal Dialysis?

Yes, peritoneal dialysis is used frequently in the diabetic patient. This form of treatment involves using the membrane that lines the patient's abdominal cavity (peritoneum). During minor surgery a soft plastic tube is placed into the abdominal cavity. Special fluid (peritoneal dialysis solution) is drained into the abdomen and allowed to remain in the abdominal cavity for a few hours, and is then drained. During this process (exchange), waste products are transferred from the blood to the solution. This procedure eliminates the waste products from the body. It takes approximately 45 minutes to drain the fluid and refill the abdominal cavity for a new exchange. After proper training the patient can perform this exchange at home and/or at work. This form of treatment is usually done three-five times each day, every day of the week. This form of treatment is called continuous ambulatory peritoneal dialysis. (CAPD).

What About a Low Protein Diet for the Prevention or Treatment of Kidney Damage?

Recent preliminary research suggests that a high protein diet can cause harm to the kidneys. It has been suggested that lowering the protein in the diet can slow the progression of kidney failure due to a variety of kidney diseases, including diabetes. It is recommended that the patient discuss this issue with his/her doctor and if any change is needed in the patient's diet, this can be done with the help of a dietitian. Patients should not start themselves on a low protein diet because it could result in poor nutrition and a decrease in general health.

What Is the Future Outlook for Patients with Diabetes?

Increased numbers of research dollars are being directed towards the understanding of diabetes. Hopefully, therapy can be based on prevention rather than supportive care in the future. However, the medical management of diabetes has also improved with the coming of home glucose monitoring, better recognition of the role of high blood pressure and its proper management, and the exciting new data on the effects of diet on preserving kidney function. When diabetes does progress to serious kidney failure, the diabetic patient can now achieve success rates with kidney dialysis and transplantation that are almost equal to those of a non-diabetic kidney patient. Pancreas transplants producing an improvement of the diabetic state are increasingly done and success rates are climbing dramatically. Thus, the future is relatively bright in terms of the breakthroughs in the understanding and management of diabetes.

What important points should the patient remember about diabetes and the kidneys?

- *Severe kidney failure is much more common in Type 1 (juvenile-onset) than in Type 2 (adult-onset) diabetes.*
- *Because diabetes may affect the blood vessels in the body, it can cause permanent kidney damage and kidney failure.*
- *Other factors besides diabetes can also cause kidney damage and failure. These factors include high blood pressure, blockage of urine flow, urinary tract infections, and certain medications (especially pain medications).*
- *Maintaining blood pressure in the normal range is the most effective and proven method for slowing the rate at which kidney function is lost.*
- *Early kidney damage by diabetes can be detected by a urine test. The most practical way to watch the condition of the kidneys is with blood (BUN and creatinine) tests.*
- *Leg swelling (edema), increased urination at night, high blood pressure, and a decrease in the amount of insulin needed to control diabetes may all be signs of kidney damage.*
- *End state kidney failure can be treated by kidney transplantation, hemodialysis, and/or peritoneal dialysis. The type of treatment is chosen individually for every patient depending on overall health, lifestyle, and personal preference. A treatment plan may include each of these forms of therapy at one time or another.*
- *The diabetic diet is a very important part of the treatment of all diabetic patients.*

This publication has been based on the pamphlet entitled, **Diabetes and Kidney Disease,** published by the National Kidney Foundation of Michigan, 1985. Reprinted with the permission of the National Kidney Foundation.

The Good News/ Bad News Drug

by Robert Cooke

The good news: Cyclosporine combats the twin threats of organ rejection and massive infection — making heart transplant surgery more survivable. The bad news: A spectrum of side effects accompanies its use, some of them dangerous.

Back in the the dark ages of transplant surgery — i.e., before cyclosporine — the technical skill of the surgeon seemed almost irrelevant. The operation itself could often be described as brilliant, a real surgical *tour de force*. But efforts to keep transplanted organs from being rejected —by shutting down the patient's immune system — were often crude and heavy-handed.

The surgery might be a success, but most patients died anyway, usually of catastrophic organ rejection or massive, uncontrollable infection. There was no middle ground: Either the immune system was up and functioning, ready to reject the organ, or it was completely suppressed, unable to guard against even the most common bacteria, viruses and fungi.

Only people who received closely matched organs — usually from a sibling — had any measure of success, and even then survival was iffy. And, while kidney patients often had time to shop around for a willing, well-matched donor, heart patients faced a one-shot deal, taking whatever heart was available from some accident victim. Most heart recipients died within a year or two, although at Stanford University Dr. Norman Shumway was able to keep up to 63 percent of his patients alive for a year, pre-cyclosporine.

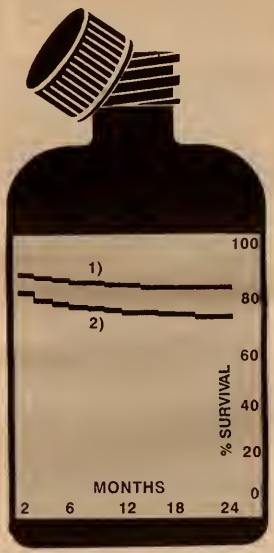
The situation changed dramatically in 1978, when the obsure drug cyclosporine entered experimental trials.

The drug had been discovered eight years earlier in a type of fungus —*Tolypocladium inflatum Gams* — found in a sample of southern Norwegian soil. It had been collected by Swiss scientists in 1970, and at first the substance it produced, cyclosporine, looked slightly promising as an antibiotic. But its anti-fungal activity turned out to be so weak that it was a pharmaceutical flop.

In taking a second look at the drug, however, immunologist Jean Borel detected unusual chemical properties: It suppressed the immune system in odd ways. Even so, his employer, the Swiss pharmaceutical firm Sandoz Ltd., remained unenthusiastic because there was little evidence that a large market existed for immunosuppressants.

Then a British researcher, David White of Cambridge, heard Borel's description of cyclosporine at a scientific meeting in 1976. White and his colleague, pioneering transplant surgeon Roy Calne, began experiments in animals and were so impressed that they urged Sandoz to continue development of the drug.

In Sandoz's first clinical trials, human volunteers were given doses of cyclosporine in powdered form carried in small gelatin capsules. But the drug was not absorbed; it passed all the way through the digestive tract and never reached the bloodstream.



Effect of Immunosuppressant Drugs on Survival

1) TRIPLE THERAPY*

*Treatment involves the use of cyclosporine, azathioprine and steroids.

2) ALL PATIENTS

Suspecting that packaging was the problem, Borel tried cyclosporine on himself after dissolving it in alcohol and other fluids, including water. After swigging down his distasteful mixture, Borel reported feeling dizzy, and cyclosporine was detected in his blood, proving it could be absorbed.

Borel found that, unlike other Immune-suppressing drugs, cyclosporine very selectively inhibits only a part of the immune system. More recent research has shown that the drug alters the activity of specific cells in the immune system, stopping so-called helper T-cells from producing a hormone-like agent called interleukin 2. Shutting off interleukin 2 production keeps another class of white blood cells, killer T-cells, from trying to kill the transplanted organ, which they see as an intruder.

According to Dr. John Najarian, chief of surgery at the University of Minnesota Medical School, when cyclosporine was introduced for organ-transplant trials, "the impact was terrific. In most hands it improved the results by 10 to 15 percent," in terms of survival of heart patients.

"Our current survival statistics for hearts are quite remarkable; (cyclosporine) has taken it from 60 percent up to 95 percent for one-year survival, and 90 to 95 percent two-year survival," Najarian said.

In addition, the current survival rate for kidney transplants is about 95 percent for the first year, thanks in part to cyclosporine, Najarian said during a telephone interview.

"We first got it in 1978 and 1979; we were the first in the U.S. to use it," Najarian said. At Stanford, where cyclosporine was also tried quite early, the results were so impressive that conventional immunosuppressive drugs were put aside. Cyclosporine became the drug of choice for control of organ rejection in heart transplants.

But if Borel hadn't persisted in studies of the drug, it would not have become available. "They were about to throw it away," Najarian said. "But by serendipity they found it had an immnosuppressive effect."

Nowadays, patients taking cyclosporine get it in "cocktail" form, usually mixed with olive oil and then diluted in orange juice, or even milk. They must continue to take the drug for the rest of their lives, unless some other, even better form of immunosuppression is developed. The absorption of cyclosporine from a person's intestines remains variable and incomplete, but doctors generally have found that the peak concentration of the drug in blood is achieved three and a half hours after taking a daily dose.

While the exact mechanism of cyclosporine's action isn't known, scientists working with white blood cells can see that the normally round nuclei of helper T-cells assume a daisy-like shape when dosed with the drug. According to Allan Hess of The Johns Hopkins University in Baltimore, the drug may alter the structure-supporting chromosomes in the cell's nucleus, halting genetic activity in the cells.

An interesting point: This strange alteration in the shape of the T-cell's nucleus is also seen in helper T-cells infected with two cancer-causing viruses, the recently discovered HTLV-1 and HTLV-2 viruses. The change caused by the viruses seems to be permanent, while the change caused by cyclosporine is reversible. Within two hours after the conclusion of exposure to cyclosporine, the helper T-cell nuclei revert to their normal rounded shape.

As with any powerful drug, a spectrum of side effects accompanies cyclosporine's use, some of them dangerous. The most serious is kidney damage, which is particularly ironic for people who've just had a kidney transplant. But damage to kidney tissue is reversible, and can be minimized by keeping cyclosporine doses low. Patients also tend to grow more facial hair, and may have episodes of trembling.

There is also some danger that patients on cyclosporine will develop a form of cancer called lymphoma. But by balancing the doses of cyclosporine and steroid drugs such as prednisone, doctors found they could control organ rejection without seriously increasing the risk of lymphoma. Experience also has shown that, despite much-publicized claims by French researchers, cyclosporine should not be used against AIDS, the deadly acquired immune deficiency syndrome; it exacerbates destruction of the immune system.

As experience with cyclosporine mounts, Najarian said, researchers at Sandoz "are very active, finding out how to make it less toxic. The company is working like crazy."

In his own laboratory, Najarian said, "we're also working on that. We're reducing the dose, and combining it with two other agents, and it is working well." This approach, called "triple therapy," involved the combined use of cyclosporine, another immunosupressant drug called azathioprine (marketed as Imuran) and steroids. Triple therapy is also being used in other organ-transplant centers.

Sandoz is the only producer of cyclosporine, Najarian said, and "they are making billions of dollars on it" now that the drug's effectiveness has been demonstrated. The annual cost of cyclosporine for a transplant patient, he said is about $7,000.

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"Transplant Games" Put Focus on the Need for Kidney Donors

by Dan Garcia

(Editor's Note: The following is from an article published in the *Star Ledger,* of Newark, N.J., September 6, 1987.)

Kidney transplant recipients are so grateful to be unshackled from dialysis machines that they want to do something "every minute of our lives," says transplant patient Carol Anderson of Randolph, New Jersey.

Anderson, 33, was among four New Jerseyans on a 60-member American contigent to the World Transplant Games in Innsbruck, Austria, on September 17-20, 1987. The Olympics-format Games, which began in 1980, are a way for participants from around the world to celebrate the newly mobile lives they lead as a result of transplants.

But Anderson, who does volunteer work for the Red Cross, said the participants also hope to draw attention to the thousands of others who must wait for kidney transplants because of a lack of donors.

"We want to show that these operations are beneficial, that we don't just lie around afterwards," Anderson said. "We realize how lucky we are to be able to move around, and we want to go out and do something every minute of our lives."

"But people still think that if they're donors, their bodies will be mutilated when they die. A lot of organs are being buried today."

Anderson, a diabetic, required four-hour, thrice weekly treatments by a dialysis machine for 1½ years. In 1984, her sister, Laurie A. Jerson, 28, donated a kidney for Carol's transplant operation at the Cornell Medical Center in New York City.

Eleven countries were represented at the World Transplant Games in Austria. There were competitors in track and field, cycling, swimming, tennis, golf, badminton, table tennis, and other events.

Kathy Sagal, a spokeswoman for the Health Care Finance Administration in Baltimore, said the demand for healthy kidneys outstrips the supply.

In 1976, she said, 3,504 patients received kidney transplants in the United States. In 1986, the number jumped to 8,976. However, 11,108 people are on waiting lists for a kidney, she said.

"There are never enough donors," Sagal said. Of the 8,976 kidneys transplanted last year, 7,089 were "cadaveric" — taken from donors within 72 hours of death — and 1,887 came from relatives, Sagal said.

Pat O'Conner, a spokeswoman for the National Kidney Foundation in New York City, said, "We have public service annoucements on TV and radio, and we try to place ads around New Year's Day to get people to make resolutions to donate organs. The organ-donor cards we provide are more symbolic than anything. If somebody dies in a hospital, nobody goes looking to see if they have a donor card."

Carol Anderson has had a kidney transplant for 3½ years. She tells how being unshackled from dialysis makes her feel "stronger and more energetic."

However, O'Conner said several states have enacted laws that require nurses and doctors to inform the next of kin that they may donate the organs of a deceased patient.

Anderson said donor awareness is vital today because transplanted kidneys are being rejected at a lower rate. She estimated that 60-65 percent of transplanted cadaveric kidneys are accepted, and that 95 percent of kidneys from relatives are accepted.

She said the use of immunosuppressant drugs such as Cyclosporin and Prednisone have increased the success rate of transplant operations.

"We have to take these powerful drugs the rest of our lives and they have some side effects, but when you're off the dialysis machine, you feel stronger and more energetic," Anderson said.

Anderson said she won the table tennis competition at the National Transplant Games in Fort Worth, Texas, in 1986.

"It's no big deal to anyone else," she said. "But it's a big deal to us."

Fred Moses, 29, a pharmacy technician in East Orange, New Jersey, was on dialysis treatment for five years before he got a kidney transplant at St. Barnabas Medical Center in Livington, New Jersey, in 1983. Moses now runs five miles a day and competed in at least eight races in 1987.

"I have a lot more energy than I used to have," he said. "My new kidney is cleansing my blood and producing oxygen and red blood cells and strengthening my bone marrow. When you're on dialysis, your blood is being cleansed, but you're not making any new cells."

Routine Inquiry for Organ and Tissue Donation

The National Kidney Foundation

A majority of state governments now require hospitals to ask family members when a relative dies if they will agree to donate the family member's kidneys or other organs and tissues. This wonderful gift saves lives and helps patients with chronic illnesses to have more productive and rewarding lives. Your state may already have such a rule, called "routine inquiry" or "required request," The National Kidney Foundation wants you to know more about "routine inquiry" so that you can choose to make the "Gift of Life" when a loved one passes away.

What Is Routine Inquiry or Required Request?

Routine inquiry or required request provides a system for hospitals to identify potential organ and tissue donors at the time of death. One of the hospital's staff members, the family's doctor or a member of the clergy consults with the family as to their wishes concerning organ and tissue donation. The state does not require donation.

To What Extent has Routine Inquiry Increased Organ and Tissue Donations in the States Where it has been Implemented?

Routine inquiry has already had a significant impact on organ and tissue donation. In those states having the longest experience with routine inquiry, organ and tissue donations have increased approximately 50 percent. This increase can be attributed to vigorous public and professional education programs concerning this legislation conducted by National Kidney Foundation Affiliates and other transplant organizations.

Why Do We Need Routine Inquiry?

8,500 Americans are waiting for new kidneys and thousands more need heart, liver, heart-lung and pancreas transplants to survive. In addition, cornea and their tissue transplants also improve the quality of life. A recent Gallup Survey showed that 72% of those polled would be *very likely* to give permission for the donation of a loved one's kidneys after death. Unfortunately, each year no more than 15 percent of the 20,000 persons who might serve as organ donors at death actually do so, because their families are not presented with the opportunity. Routine inquiry offers the opportunity to everyone.

Are Organ and Tissue Transplants Experimental?

No, they have been performed routinely for more than 30 years. In 1986 approximately 10,000 kidney transplants were performed. New medications and better postoperative care have improved the success rate for kidney transplants to almost 70-90%. Similar advances have occurred in other transplants.

Must the Family Agree to Organ or Tissue Donation When Asked?

Family wishes are always respected. The family always has the right to decline.

What are the Ethics of Organ and Tissue Donation?

Religious leaders the world over favor such donations as expressions of the highest humanitarian ideals. The gift of an organ or tissue essential to the life of another human being is consistent with principles of religious and ethical systems everywhere. If you have any questions in this regard, consult with your minister, priest or rabbi.

What About Those Whose Personal Beliefs Oppose Organ and Tissue Donation?

Those who are opposed to organ or tissue donation for whatever reason may simply decline. The same is true if the deceased was opposed to donation.

Will Organ or Tissue Donation Affect Funeral and Burial Arrangements?

No. Donation of organs or tissues for transplantation will neither alter the deceased's appearance nor interfere with customary funeral or burial arrangements. Funeral and burial arrangements remain the responsibility of relatives or persons in charge of the estate.

Are There Any Costs to the Donor Family?

No.

How Can the Family Know the Deceased's Wishes?

The deceased may have previously signed an organ donor card or have indicated the desire to do so. It is very important that individuals discuss their feelings about organ and tissue donation with their families or loved ones. If the feelings of the deceased are unknown, family members have a right to authorize the gift on his or her behalf.

What if I Need to Know More About Routine Inquiry or Organ Donation?

Your local National Kidney Foundation Affiliate will answer any questions you may have about "routine inquiry" and organ donation. Organ donor cards are available from your local National Kidney Foundation Affiliate or the National Kidney Foundation, Inc., 2 Park Avenue, New York, NY 10016. Toll-free phone 1-800-622-9010.

(Note: The above was reprinted from a pamphlet published by the National Kidney Foundation with their permission.)

First Word

by Gail Marell

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We were excited about having another child. During the eight months I was pregnant, the baby was the center of our attention. We planned for and dreamed about the new addition to our family and were eager for our child's arrival.

Pregnancy is the most unusual time in a woman's life. It's a time filled with constant emotion, anticipation, excitement, and fear. I don't know any woman who hasn't at some time during pregnancy become obsessed with the possibility of something going wrong with her baby. Nine months is a long time — a time when almost all of your thoughts focus on the miracle of the new life growing inside of you.

It was the beginning of my ninth month when a somewhat routine sonogram revealed that the nightmare was indeed a very concrete reality. Our doctor's voice was filled with pain as he explained that our baby suffered from a birth defect called anencephaly. We listened in horror as he told us that our baby's brain and skull had not developed. There was only a brain stem. Our baby would die at birth or shortly thereafter.

As he explained our options I knew that I had to terminate the pregnancy as soon as possible. Our doctor encouraged me to carry the child to full term, but feeling the baby grow and kick for another month was more than I could bear. I needed to get through the delivery and get on with my life. Sometime during that night, as we went over and over what was happening to us, we began to think about all the appeals from the anguished parents of children awaiting liver, kidney, and heart transplants. The brain stem, we were told, is the portion of the brain that controls functions such as breathing and heartbeat, so our daughter's body organs had developed normally. We began to wonder about the possibility that any of our baby's organs could be useful to another baby. Maybe our baby's organs could give a sick child a chance to live. Maybe we could find something good in our tragic situation.

When we arrived at the hospital early the next morning, we were aggressive about our wish to donate our baby's organs.

The hospital staff, however, didn't know the answers to all of our questions. They did know that removing the organs of an anencephalic infant was a clouded issue and warned us not to get our hopes up. Nonetheless, it served as a goal.

All that long day and night we grasped at the prospect of finding something positive. Our obstetrician made some inquiries, only to find out that California law would not permit us to help children desperately in need of organ transplants. All the other states have similar rulings. The law says that a person must be "brain dead" before organs can be removed for transplant. It rigidly defines this condition as the "irreversible cessation of all functions of the entire brain, including the brain stem. "The law does not allow parents to donate a baby's organs as long as the brain stem continues to function. The absence of a brain makes no difference. It's a catch-22: Once the brain stem stops, the organs give out, and it's too late for them to be useful.

There was nothing more we could do. The next morning we tried to induce labor. That was unsuccessful, so I had a Caesarean section. Our daughter lived for three hours.

The law seemed so wrong. How could anyone consider the quality of my daughter's short life above the life of a child who could have a chance? Who benefits from this law? My daughter felt no pain. My daughter had no consciousness. But there are hundreds of babies born with birth defects that could be corrected if the necessary organs were available.

Each year 400 to 500 children suffer from lethal kidney disease. An additional 400 to 500 children have congenital heart disease. Yet another 500 suffer from deadly liver failure. There is a very limited supply of these greatly needed organs. Some of these children could be saved through transplants from anencephalic organ donors. Each year about 3,500 anencephalic babies are born in the United States. It seems such a terrible waste to have the medical technology available to save a sick child's life and not be allowed to use it.

Our sorrow did not go unheeded. State Senator Milton Marks (R-San Francisco) read in a local paper about our unsuccessful attempt to donate our baby's organs. In May 1986 Marks introduced a bill to the California legislature in which this phrase would be added to the statute: "In addition, an individual born with the conditon of anencephaly is dead." To Marks' surprise, the bill was met with strong opposition and failed to meet a legislative deadline for 1986. We hope the bill will be reintroduced in 1987.

As a society we must respect and protect life. The "brain death" laws were written to protect people with severe brain damage. These laws should guard life as long as there is any hope of survival. The baby born with anencephaly, however, is born dying. There can be no reversal. There is no hope for survival. The life cannot be saved. But that life could save others.

The law should be changed. *Brain absent* should be redefined as "brain dead." Anencephalic babies should be the only exception made to the law. Hospitals and doctors should be able to present parents of anencephalic babies with the option of donating their child's organs. It's a horrible, difficult situation, but the opportunity to have helped someone else through a difficult situation would certainly have eased my mind.

Gail Marell, her husband, their 4½-year-old son and their dog Sam live in Oakland, California.

Postscript: Donna Siebert, one of the California representatives for The Diabetics Division of National Federation of the Blind, reports that the office of California Senator Milton Marks says that the bill was not reintroduced in 1987.

The Power of the Pen

Exercising your right to be heard is more than a privilege — it's a responsibility.

by Richard Cizik

1. Concentrate on your own delegation. Your two senators and your representative(s) are obligated to consider your views.

2. Confine your letters to one specific legislative subject. This ensures that it will be seen by the right staff member. Addressing many subjects weakens your argument and complicates any response to it. Also, tell the legislator exactly what you want done.

3. Ask the legislator to tell you his position on the matter. Will he support or oppose the legislation? He has a responsibility to inform you of his stance.

4. Write in your own words. Mass-produced letters that are part of a mail campaign or petition drive wield little influence. Your congressman or his staff assistant will measure your interest in an issue by the amount of time you take to inform him of your beliefs. A simple two- or three-sentence personal letter has more impact than a preprinted postcard.

5. Be brief. Letters that are longer than one page tend to be saved for another day's reading. Completeness and clarity are both possible on one page. It will take more effort to condense your ideas onto a single sheet, but it's worth it if you want to be read. Letters need not be typed, but they must be legible.

6. Give your reasons for taking a stand. But avoid emotional arguments or language that is demanding or threatening. While the subject may be emotion laden, use facts and illustrations to make your point. Statements like "Vote against HR100; I'm bitterly opposed" will not help much.

But a letter which says, "I'm a small hardware dealer, and HR100 will put me out of business for the following reasons ..." says much more.

If you disagree with your legislator, say so but do not berate him. Keep the dialogue open.

7. Do not assume that your legislator is well-informed about a given issue. He can't stay on top of everything. Explain the situation as it concerns you.

8. Be constructive. Though it is fine to indicate how a bill may be counterproductive, be sure also to add your thoughts on positive measures that can be taken in lieu of it.

9. Ask for a response. Request an answer to a specific question. A well-formulated inquiry will often get a more personal response.

10. Be timely. Read the newspaper or institutional newsletters, such as

(Continued on page 23.)

Diabetes: Devastating Disease, Both Physically and Financially

by Susan Manchester

Susan Manchester, a long-term diabetic, tells how diabetes can knock you out both physically and financially.

It is a truth that needs no retelling, that for those of us who are long-term, juvenile onset, Type I, insulin dependent diabetics, this disease can both knock you out physically and wipe you out monetarily. Now ranking in the United States as the third leading cause of death by disease and the leading cause of new blindness, it is most definitely a health hazard to be reckoned with.

Diabetics who find their bodies afflicted by such major complications as renal failure, amputation, and blindness, not only are faced with the devastating adjustments to their lifestyle that such problems demand, but must also confront the fact that employment is difficult to find, as is the adequate insurance needed to pay for the astronomical medical expenses these complications generate.

I have spent several months researching this weighty problem and would like to share my findings with you.

MEDICARE: Provides good basic coverage; however, deductibles are costly and require supplemental insurance to cover. No drug coverage, aside from one-year coverage of immuno-suppressive drugs following organ transplant. (Not too impressive, considering these must be taken for life.)

MEDICAID: Frequently substituted for Medicare when one is not eligible. Half subsidized Federally, half state, it varies greatly by the state in which one lives. Income must be minimal to qualify. Also, it is common practice for physicians to limit number of Medicaid patients, thus forcing recipients to find less skilled doctors. Coverage includes hospital, physicians, and drugs.

H.M.O.: The H.M.O., or Health Maintenance Organization, is a good basic insurance plan, with a few exceptions. Although it covers doctor visits in full, as well as hospitalizations, it has both a deductible and a maximum on drugs. It is expensive when purchased privately.

STATE SUBSIDIZED DRUG COVERAGE: This is a plan currently in force in only three states — Pennsylvania, New Jersey, and Connecticut — and is very good. If one meets the eligibility requirement for income, which is not severe, all prescription drugs cost $4.00. If a generic substitute is available, you must accept it in place of the brand name. Connecticut expects this program to cost approximately $50 million per year, but it is subsidized in full by the lottery. Only the "elderly," that is, over 62, or handicapped are eligible.

Since each of these plans has its limitations, what next? I asked this of some dozen legislators, both senators and congressmen, and found an encouraging response from all. I have chosen two senators to represent both sides of the aisle, and have included the heart of their response.

SUBJECT: Catastrophic Illness Legislation.

Lowell P. Weicker, United States Senator — Republican. "S1127, the Castastrophic Loss Prevention Act, is being considered by the Senate. This legislation would limit out of pocket expenses for costly acute care (catastrophic care) for Medicare recipients. The Part B, out of pocket costs, would be held to just above $1,000 per year, but does ALLOW THE COSTS OF IMMUNO-SUPPRESSIVE DRUGS LIKE CYCLOSPORINE TO BE PUT TOWARD THE PART B COST SHARING LIMIT. While S1127 will not assist persons not on Medicare, or whose incomes exceed Medicare eligibility, this legislation is a starting point for a more even-handed and affordable means of health care."

Edward M. Kennedy, United States Senator — Democrat. "Coverage for immuno-suppressive drugs is included in the 'Catastrophic Illness Health Insurance' Bill, recently passed by the House of Representatives. I intend to work hard to insure that it is included in the Senate Bill. No organ transplant patient should ever be denied essential drugs because of the lack of insurance coverage, and I believe the Congress is on the verge of correcting this inequity."

Please add your voices to support S1127.

As to the less costly, but most unfair problem faced by the diabetic — insurance that will not cover insulin or syringes — I urge you to address this nonsense to your State Insurance Commission, if you have one. If not, the time has come to bombard the State Legislature to change these unfair practices. I urge you all to write to these groups and make known your feelings. The pen is still mightier than the sword.

My Pancreas Transplant

by Dan Krikac

I had just been to my doctor, a diabetes specialist, for the fourth time that month. I had recently had laser surgery on my eyes and undergone vitrectomy surgery on my left eye. The week before, my wife and I were the proud parents of twin girls. That made me start thinking of my future and where I was going to be. I was told by my doctor that I would face a kidney transplant in three to five years. I was really scared. I had known the University of Minnesota was doing successful pancreas transplants and I asked my doctor if he could check into them for me. He did, and within a few months, I was at the University having a work-up for the transplant. My thinking at this time was that if I got a successful pancreas transplant, perhaps I could ward off the kidney disease.

Dan Krikac has had two pancreas transplants and tells of the benefits and the drawbacks.

The tests that they ran on me when I had my transplant work-up were: Glucose tolerance, nerve function, treadmill, EKG, 24-hour profile, visits by social and psychiatric workers, and a kidney biopsy. These tests took place over a period of a week or so.

I had successfully completed my work-up and was now ready for the real thing. I needed preliminary surgery done in order to prepare a place for my transplant. This surgery is called a Roux-eny. This is where they prepare a connection in your intestine. For this surgery, I was in the hospital for five days.

I received my call for my transplant in April 1985. It was on a Sunday and when you live in a remote place such as Rapid City, S.D., there aren't that many flights out on Sunday. So, my wife, children and I chartered a flight, but because of bad weather we were able to fly only half-way, where we met my parents who drove us the other 275 miles to Minneapolis.

One thing led to another. We got to the hospital in time, they prepared me for surgery that evening and early the next morning I was in surgery. The surgery went well but I developed an abscess in the transplanted pancreas, and it had to be removed two weeks later. I was back at square one. I didn't know what I was going to do — go back on the cadaver list and go through surgery again, or quit and suffer the consequences. I opted to go on the cadaver list and try it one more time. Total doctor and hospital bill: $70,000.00.

My second transplant call came in March 1986, and my trip to Minneapolis went much smoother. I still couldn't get a flight, so I again had to charter a plane to Minneapolis. I was familiar with the pre-surgical procedures this time, which made it much easier to get ready for the surgery itself. The surgery went well. I was out in six hours. The first three days or so are the worst. You feel like you've been hit by a semi-truck. I felt much different than I did following my first transplant. I felt more active; I wanted to get up and move around. With each day I started feeling better. The worst part of the transplant procedure is having an NG (naso-gastric) tube running through your nose and down to your stomach.

(Continued on page 23.)

The Power of the Pen

(From page 21.)

NAE Insight, for dates of scheduled floor votes or committee action. You should write as early as possible before decisions are made. By doing so, it's possible to encourage the legislator to take the right position and influence his colleagues before the opposition captures his attention.

11. Be accurate and courteous. Make certain that your name and address are on both the envelope and letter.

Use proper etiquette. Every legislator is addressed as "Honorable" on the envelope and inside address. In the salutation, however, representatives are addressed as "Mr.," "Ms." or "Mrs." while senators are called "Senator."

12. Point out the moral issues involved. Because legislators get so much mail from special interest groups, they need to hear from citizens who are primarily concerned with what seems right to them on moral grounds.

13. If you have expert knowledge, share it. Of all the letters that pour into a congressman's office, perhaps one in a hundred comes from a constituent who is an expert on the matters at hand. Every opinion is important, but those from someone with real experience are a gold mine to conscientious politicians.

14. Say "well done" when deserved. Members of Congress are human, too, and appreciate a word of thanks from people who believe they have done the right thing. Very few constituents bother to thank them. (It is best to do so while the vote is still fresh in the congressman's mind.)

15. Avoid becoming a constant "pen pal." Write when you feel compelled, but don't try to instruct your congressman on every issue. A common pet peeve on Capitol Hill is the "pen pal" who weighs down the mail every few days with long tomes on every conceivable subject.

16. Always keep copies of correspondence. Retain and file a copy of your letter and the reply from your representative. They are especially useful should you arrange an interview to discuss your concerns.

17. Try a joint effort. Join with others, if possible, to write your individual letters in a group. There is motivation and support in numbers. If you've never written to a legislator, someone else's experience can be an encouragement. If you receive a negative response, it helps to have others with whom to talk it over.

Above all, do not get discouraged. Remember, your legislator needs your help in casting votes. The "ballot box" is not far away. It's painted red, white and blue, and it reads "U.S. Mail."

(Note: This article appeared in the December, 1987 issue of the *The Blind Missourian* a bi-monthly magazine published by the National Federation of the Blind of Missouri.)

National Federation of the Blind

(From page 9.)

a central question of a custody suit. Because the National Federation of the Blind was not contacted, it is already too late for some blind mothers and fathers. The organization is determined to establish sound case law on this issue.

The NFB Is Important To You

Blindness knows no discrimination. Any child can be born blind. Any individual can become blind in childhood or in later life. It is in the best interest of every individual to understand blindness and how to cope with its problems.

You Can Help

The most important thing you can do is help us spread the new concepts about blindness. When you see our literature in the mail or meet one of us on the street, remember that we are people, just like you — with all the range of talents and capacities, wits and wants that you possess. You can also help by making cash contributions to our organization or remembering the National Federation of the Blind in your will. The National Federation of the Blind is principally supported by public contributions. Donations are tax deductible.

Members-At-Large

Interested sighted people are encouraged to join the National Federation of the Blind. You can help us in our work by becoming a member-at-large and an Associate. Associates receive regular mailings providing updated information of programs and activities of the organization. Many sighted people have already become Associates in the following classifications:

Associate — $10
Contributing Associate — $25
Supporting Associate — $50
Sponsoring Associate — $100
Sustaining Associate — $500
Member of the President's Club — $1,000

To become a member-at-large send your name, address, and your dues and Associate contribution to: **The National Federation of the Blind, 1800 Johnson Street, Baltimore, MD 21230**

The Courtesy Rules of Blindness

When you meet me don't be ill at ease. It will help both of us if you remember these simple points of courtesy.

1. I'm an ordinary person, just blind, You don't need to raise your voice or address me as if I were a child. Don't ask my spouse what I want — "Cream in the coffee?" — ask me.
2. If I am walking with you, don't grab my arm; let me take yours. I'll keep a half-step behind, to anticipate curbs and steps.
3. I want to know who's in the room with me. Speak when you enter. Introduce me to the others. Include children, and tell if there's a cat or dog. Guide my hand to a chair.
4. The door to a room, cabinet, or to a car left partially open is a hazard to me.
5. At dinner I will not have trouble with ordinary table skills.
6. Don't avoid words like "see." I use them, too. I'm always glad to see you.
7. I don't want pity. But don't talk about the "wonderful compensations" of blindness. My sense of smell, touch or hearing did not improve when I became blind. I rely on them more and, therefore, may get more information through those senses than you do —that's all.
8. If I'm your houseguest, show me the bathroom, closet, dresser, window — the light switch, too. I like to know whether the lights are on.
9. I'll discuss blindness with you if you're curious, but it's an old story to me. I have as many other interests as you do.
10. Don't think of me as just a blind person. I'm just a person who happens to be blind.

In all 50 states, the law requires drivers to yield the right of way when they see my extended white cane. Only blind may carry white canes. You see more blind persons today walking alone. Not because there are more of us, but because we have learned to make our own way.

My Pancreas Transplant

(From page 22.)

The NG tube remains inserted from ten to 14 days and gets to be a bit uncomfortable. I remained in the hospital for three and a half weeks. Total doctor and hospital bill $40,000.00.

Your problems do not end just because you've had a pancreas transplant. The transplant gives you a whole new set of problems. For instance, you may not have insulin reactions any more, but you do have rejection episodes. I've had two episodes of rejection. I've come down with CMV (Cytomegalovirus), a flu-like virus that hangs on and on. Since my transplant, I have been hospitalized on five different occasions. Problems do arise, and they need to be handled right away, which makes for frequent return trips to Minneapolis.

I am required by the University of Minnesota Transplant Center to take my temperature, weight, fasting blood sugar, and blood pressure daily; and every other week I have tested at the laboratory: hemoglobin, white blood count, BUN, creatinine, sodium, potassium, calcium, phosphorus, magnesium and Amylase. Immediately post-transplant, I did these lab tests twice a week for six months, then I did them weekly for six months, and now, 17 months post-transplant, I am doing them every other week. If I go on vacation and that week is a lab week, I have to make arrangements at a local hospital to have these tests done. Total cost to maintain these lab tests is approximately $8,400.00 a year.

Immuno-suppressive therapy medicine is expensive with cyclosporine being the most expensive. One bottle costs from $140.00 to $180.00 and lasts me about five days. This amount varies from patient to patient. The second most expensive drug is Imuran costing about $100.00 a month. The most affordable is Prednisone. Each of these drugs has their own side-effects; Prednisone causes aches and sore joints, and cyclosporine can damage the kidneys, as it is doing in my case. My kidneys were already damaged by diabetes and now the cyclosporine has damaged them further. I am now on the cadaver list for a kidney transplant at the University of Minnesota.

I have had many benefits and many positive things because of this transplant, with the most important being that my retinopathy has stabilized; my neuropathy has also stabilized, if not reversed. Another important benefit is the psychological uplift you get from always being in control of your blood sugars and the psychological benefit of having your friends, church and family members behind you 100% both physically and financially. Without the support of these people the transplant would not have been successful.

I don't want this to sound like a financial report, but I want you to know that the pancreas transplant can be a very expensive, time consuming, and emotionally draining experience. Make sure before you decide to get a pancreas transplant that you read your insurance policy from cover to cover and have some money raised for those uncovered items that always seem to crop up.

If given the opportunity to do this again, I would do it, as it has brightened my future immensely. I wish good luck to any of you who face a pancreas transplant.

Karen Derrick is a registered dietitian at the Veteran's Administration Hospital of Columbia, Missouri. She is an insulin dependent diabetic who graciously calculates the diabetic exchanges and food values for our recipes.

Send your great ideas to the editor. He is the official taste tester and needs recipes to test his taster.

Meat Loaf (Microwave)
by Frances Allen
from Columbia, MO

1 1/2 lbs. lean ground beef
1 egg, slightly beaten
1 cup bread crumbs
2/3 cup milk (2%)
1 small onion, chopped
1 jar (2 1/2-oz.) sliced mushrooms drained
1 Tbs. Worcestershire sauce
1/4 tsp. black pepper

1.) Mix together all ingredients. Shape into loaf. I use a round tube microwave pan.

2.) Mircrowave on medium high (70%) for 22 to 24 minutes or no longer pink. Allow to stand covered 5 minutes before serving.

Yield: 12 servings; Calories: 140; Diabetic Exchanges: 2 meat.

Clam Chowder
by Alma Ausburn
from Columbia, MO

2 cans clam chowder (10 3/4-oz.)
2 cans potato soup (I cook potatoes and make my own)
2 cans cream of celery soup (10 1/2-oz.)
1 can evaporated milk (8-oz.)

Cook low 4-6 hours in crockpot. If fixing on stove, stir constantly.

NOTE: In making large recipe I cut down on proportion of clam chowder to rest of ingredients.

Yield: 8 servings (1 cup per serving); Calories: 180; Exchanges: 1 Bread/Starch, 1/2 milk, 1 1/2 fats.

Zucchini Bread
by Dolores Olson
from Tempe, AZ

1/3 cup sugar
1/3 cup oil
3 beaten eggs
1 1/2 tsp. orange peel
1/2 tsp. vanilla
2 1/4 cups flour
1/2 tsp. salt (scant)
1/4 tsp. mace
1 tsp. soda
1 tsp. baking powder
3 tsp. cinnamon
1/4 tsp. ginger
2 cups shredded zucchini
1/2 cup chopped walnuts

Beat sugar, oil, eggs, orange peel and vanilla togther until well blended. Add dry ingredients and zucchini alternately. Stir in nuts. Bake in two medium-sized loaf pans (sprayed with Pam) at 375 degrees for about 40 minutes (till toothpick comes out clean).

NOTE: I have adapted this recipe for low sugar, fat and salt from a recipe which contains 1 cup sugar, 1 cup oil, 3 cups flour and 1 tsp. salt. I find this reduction just as tasty, but if desired one may use the original amounts or any variation between that and my reduction.

I have had several requests for this zucchini bread recipe (even from non-diabetics) and we find it very tasty.

Carbohydrate Content: If each loaf is cut in 16 slices, each slice contains 9 gm. CHO. Yield: 24 slices; Calories Per Serving: 125; Diabetic Exchanges: 1 Bread, 1 Fat.

Pecan-Cheese Crispies
by Ida Bulgin
from Columbia, MO

1 cup shredded Velveeta cheese (8 ounces)
1/2 cup margarine, softened (not melted)
1/8 tsp. hot sauce
1/4 tsp. dry mustard
1 cup all-purpose flour, sifted before measuring
1 tsp. baking powder, sifted with flour
1 cup crispy rice cereal (Rice Crispies)
Pecan halves

Combine cheese and margarine with slotted spoon or fork until blended. Add hot sauce and mustard while blending above. Gradually add flour and baking powder, mix; stir in cereal. On ungreased cookie sheet shape dough into 1-inch balls, flatten with a fork in crisscross design. Press a pecan half in center of each cookie. Bake at 350 degrees for 12 to 14 minutes or until slightly browned. Should be crisp but not crumbly. Cool before lifting with spatula or pancake turner.

Yield: 24 cookies; Calories Per Serving: 100 per cookie: (?) Diabetic Exchanges: 1/3 bread, 1 1/2 fat.

Lo-Cal Grasshopper
by Linda Carstens
from Virginia, MN

1/3 cup powdered milk
1/2 cup cold water
1 tsp. vanilla
1/4 tsp. or less mint extract
2 tsp. sugar substitute
2 drops green food coloring
6-8 ice cubes, crushed

Mix in blender at medium speed until thick and creamy.

Yield: 1 12-oz. glass; Calories: 90; Diabetic Exchanges: 1 skim milk

How to Cook Husbands

MFA Cook Book, 1946 Publication

Submitted by Frances Allen from Columbia, Missouri

A good many husbands are entirely spoiled by mismanagement in cooking and so are not tender and good. Some go about it as if their husbands were bladders and blow them up. Others keep them constantly in hot water. Others let them freeze by their carelessness and indifference. Some keep them in a stew by irritating ways and words. Others roast them. Some keep them in pickle all their lives.

It cannot be supposed that any husband will be tender and good managed in this way, but they are really delicious when properly treated.

In selecting your husband, you should not be guided by the silvery appearance, as in buying mackerel, nor by the golden tint, as if you wanted salmon. Be sure and select him yourself as tastes differ. Do not go to market for him, as the best is always brought to the door. It is far better to have none, unless you will patiently learn how to cook him.

A preserving kettle of the finest porcelain is the best, but if you have nothing but an earthenware pipkin it will do, with care.

See that the linen in which you wrap him is nicely washed and mended, with the requisite number of buttons and strings nicely sewed on. Tie him in the kettle by a strong silken cord, called comfort; duty is apt to be weak. Husbands are apt to fly out of the kettle and be burned and crusty on the edge, since like crabs and lobsters, you have to cook them while alive.

Make a clear, steady fire out of love, neatness and cheerfulness. Set your husband as near this as seems to agree with him. If he sputters and fizzes, do not be anxious. Some husbands do this until they are quite done.

Add a little sugar in the form of what confectioners call kisses, but no vinegar or pepper on any account. A little spice improves him, but it must be used with judgment.

Do not stick any sharp instrument into him to see if he is becoming tender. Stir him gently; watch the while, lest he lie too flat and close to the kettle and so become useless. You cannot fail to know when he is done.

If thus treated, you will find him very digestible, agreeing nicely with you and the children, and he will keep as long as you want, unless you become careless and set him in too cool a place.

An $80.00 Discount for Glucochek S.C. Audio Monitor:

A New Blood Glucose Monitoring Instrument for the Blind Diabetic

by Ed Bryant

Around the first of October, 1987, EquiMed Medical Products, Inc., of Lenexa, Kansas, contacted me about one of their products — Glucochek S.C. Audio Monitor, a blood glucose monitor with audio output. The Food and Drug Administration had just approved Glucochek S.C. Audio Monitor, and EquiMed wanted to notify everyone of its new product.

Although blood glucose monitoring is important to all diabetics, those of us who are blind have a more difficult time testing blood sugar levels because there never has been a monitoring device with audio output that wasn't accompanied by an astronomically high price tag. With Glucochek S.C. Audio Monitor, the blind can independently and accurately check their own blood glucose levels at a reasonable price.

EquiMed contacted me because I am a blind diabetic experienced with instruments used by blind diabetics, and because I am the editor of *Voice of the Diabetic*. They made an appointment to demonstrate their audio model to me. After having examined it, checked into its qualifications, compared it to similar instruments produced by other companies, and personally tested it for about three months, I can honestly say that I am impressed.

It is easy to use. The only difficulty I encountered was getting the drop of blood onto the test strip, but this is a problem common to all instruments of this type. Instruction from a medical professional or from someone experienced with the instrument is advisable to get you started. Once you know how to operate the instrument, getting the drop of blood onto the test strip just takes a little practice.

Glucochek S.C. Audio Monitor is accurate. While trying it out I had several blood samples taken by two different pathology labs. The blood glucose readings of the two labs and that of Glucochek S.C. Audio Monitor were exactly the same.

EquiMed's audio model has a large digital read-out display board and it emits electronic tones to signal testing procedures and blood glucose values. For example, if your blood glucose level were 123, Glucochek S.C. Audio Monitor would relay this information to you by beeping once to signify the numeral "1," pausing, then beeping twice to signify the numeral "2," pausing again, then beeping three times to signify the numeral "3."

Glucochek S.C. Audio Monitor is cheaper. Only two other companies manufacture blood glucose devices with audio monitors. One company offers a speech module that is attached to a blood glucose analyzer. The price of the speech module is $420; the analyzer units run from $189 to $209. All accessories are extra. The other company offers a portable talking blood glucose meter at $479.95. All accessories are extra. The regular price of Glucochek S.C. Audio Monitor with all its accessories — audio monitor, guide for application of blood onto strip, duo-set carrying cases, 25 test strips, alcohol applicator, cleaning brush, confidence check strip, cassette tape instructions, large type or picture instructions, and Braille instructions — comes to $479.95. As a special-promotion offer, EquiMed is taking $80.00 off its regular $479.95 for National Federation of the Blind purchasers.

To take advantage of this offer, just mention on ordering that you heard about Glucochek S.C. Audio Monitor through the National Federation of the Blind (NFB). This reduced price of $399.95 includes a $30.00 certificate payable to the health professional of your choice to demonstrate the instrument. On ordering the audio monitor, be sure to include the health professional's name and address. A certificate will accompany the Glucochek Audio Model to be signed by the health professional and the user, and then returned to EquiMed. EquiMed, in turn, will mail a check in the amount of $30.00 to the medical professional. Neither of EquiMed's competitors includes a professional demonstration in its price. One supplies instructions with its monitor but not a professional demonstration. The other recommends a professional demonstration but no provision for it is included in its price. Furthermore, EquiMed has offered to name a substantial contribution to the National Federation of the Blind for the sales initiated by us.

For dealers, distributors, and health educators, EquiMed is offering a 24-minute video tape free of charge. To order, contact EquiMed Medical Products, Inc., 8347 Melrose Drive, Lenexa, Kansas 66214. Their toll-free phone number is 1-800-452-7536. If you are calling from Kansas, call 913-541-0800.

When filing the necessary insurance forms, your need for a blood glucose monitor with audio output must be documented by a physician. Be sure to put on the form that Glucochek S.C. Audio Monitor has audio output.

To receive the extra reimbursement to cover specially-adapted equipment, such as the Glucochek S.C. Audio Monitor, the physician must also specify that the patient is blind or visually-impaired.

EquiMed will assist anyone who needs help filling out the necessary forms. Just call one of the telephone numbers listed above.

I am a totally blind diabetic, and with Glucochek S.C. Audio Monitor I can test my own blood glucose levels without assistance and without problems, and I know many other blind diabetics who can do the same. As the National Federation of the Blind emphasizes, blindness is not synonymous with inability.

Remember, EquiMed offers an $80.00 discount to Glucochek S.C. Audio Monitor purchasers who mention that they have heard about its audio model from the National Federation of the Blind (NFB). With discount, the cost of Glucochek S.C. Audio Monitor plus accessories and professional demonstration comes to $399.95

If you would like to learn more about Glucochek S.C. Audio Monitor, contact me, and for $1.00 I can send you a cassette tape that explains the audio model in more detail. Send your check or money order to Ed Bryant, 811 Cherry Street, Suite 306, Columbia, Missouri 65201, or call me at my office at 314-875-8911 or my home at 314-445-1928.

ADVERTISING

Advertising should capture the reader's attention. This ad being turned upside-down is one way of achieving this. We also can offer a wide selection of type styles, borders, and artwork.

Prices for color available upon request.

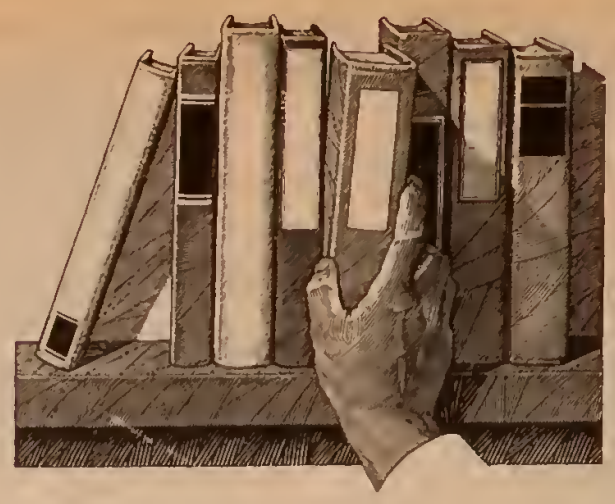
Because of popular demand we have decided to sell advertising space in **Voice of the Diabetic.** Those of you who would like to make your products or services known to the diabetic population or to health professionals involved in diabetic services or research can do so at very little cost.

Full Page	4 columns x 12"	**$300**
Half Page	4 columns x 6" 2 columns x 12"	**$150**
Quarter Page	2 columns x 6"	**$75**
Eighth Page	2 columns x 3" 1 column x 6"	**$50**

This issue of **Voice of the Diabetic** had a circulation of over 40,000 and was sent to South America, Europe, and Asia, Canada and every state in the U.S. It is subscribed to by hospitals, doctors and other health professionals, rehabilitation centers and libraries for the blind.

Anyone wishing to place an ad in our newsletter can write *Voice of the Diabetic*, 811 Cherry St., Suite 306, Columbia, MO 65201 or call (314) 875-8911.

We reserve the right to reject any advertisement, and all products advertised must carry an unconditional money-back guarantee.



What You Always Wanted to Know But Didn't Know Where To Ask

(Resource List)

About 500,00 people in the U.S. are blind, and each year 50,000 more will become blind. However, blindness does not need to be the tragedy that it is generally thought to be. With proper training and knowledge, blind people can be productive, first-class citizens. But first the blind individual must know where and how to get the training or services he or she needs.

With over 50,000 members, the National Federation of the Blind (NFB) is the largest organized group of blind people in the world. The NFB has and offers extensive information on all subjects relating to blindness and pertinent to blind people. There are many popular terms to describe us, but none of them captures the work the NFB does. For some blind people, we are the path to many services. For some, we are the way to survive while trying to get services. We are an advocacy group, a provider of legal defense, a self-help group, a government watchdog, a special interest group, and a public information center with resources available to anyone who is interested.

There are local NFB chapters in almost every city of any size in the United States. These chapters can offer any of the services the NFB has, and also arrange presentations to educate and enlighten groups interested in blindness. You are urged to contact the National Federation of the Blind for information or assistance concerning any issue dealing with blindness.

You may call or write us at our headquarters:

The National Federation
of the Blind
1800 Johnson Street
Baltimore, Maryland 21230
(301) 659-9314

Or contact your local chapter of the NFB. We're out there to help you help yourself.

The Blind At Work

The Job Opportunites for the Blind (JOB) is operated by the National Federation of the Blind in partnership with the U.S. Department of Labor. JOB is a listing and referral service for blind job applicants. The organization also produces and distributes the JOB RECORDED BULLETIN and SPECIAL BULLETIN for blind job applicants and their potential employers.

If you are blind and looking for a job, they can help you with your search. JOB provides recorded materials concerning the publications of the Department of Labor and conducts seminars for blind and blind-deaf applicants to help them learn about their skills, educate them about laws and regulations, and to encourage them as much as possible in their job search.

Hiring the blind is reasonable, proper and necessary. It is time for America to recognize the blind as a competent and energetic minority in our midst. For more information concerning JOB contact:

Ms. Lorraine Rovig
Job Opportunites for the Blind
1800 Johnson Street
Baltimore, Maryland 21230
1-800-638-7518

We do not endorse the following products but simply state their availability.

Equipment

1. Glucochek S.C. Audio Monitor: New blood glucose monitor with electronic tone signals and a large readout display board. Price includes accessories such as guide for application of blood onto strip, duo-set carrying cases, cassette, large print, and Braille instructions. *Regular price: $479.95 —Special price for NFB purchases: $339.95*

See article, "An $80.00 Discount for Glucochek S.C. Audio Monitor" in this issue of *Voice* written by our editor who has personally tested this instrument for three months.

2. Plastic Insulin Gauges: Plastic gauges are cut to fit over the insulin syringe plunger for accurate insulin measurement. Mixing insulins is possible. Cost: $1.50 per gauge plus shipping. For more detailed information contact: Boone's Kustom Kraft, 8514 S.W. 50th Ave., Portland, OR 97219.

3. Novo Pen (Insulin Delivery System): This device looks like a fountain pen but conceals a replaceable insulin cartridge. Novo Pen lets you inject insulin without manipulating vials or visually estimating dosage. A clearly audible "click" confirms the injection of each two units of insulin. Each pen cartridge contains 150 units of regular human insulin and can be stored at room temperature. Squibb-Novo Inc. says that the Novo Pen costs $95.00. We suggest that you check with your local pharmacy for price comparisons. For a pamphlet or more information contact: Squibb-Novo Inc. 211 Carnegie Center, Princeton, NJ 08540; phone toll-free: (800) 334-3678 or in New Jersey (800) 367-0249.

4. Talking Blood Pressure/Pulse Monitor: This instrument can verbally or visually give you both numbers of your blood pressure and your pulse rate. The instrument has a control that can be set to tell you, step-by-step, how to take your blood pressure or only to give you the end results. It can also be set for no verbal response at all.

This instrument is also equipped with blood pressure cuff and and LDC board on which your blood pressure and pulse rate are visually displayed. It will operate on batteries (included) or on an A/C adapter (not included). Cost: $127.95 for shipping and insurance (includes tape instructions).

Print and cassette catalogs are available. To order, contact AIDS Unlimited, Inc., 1101 N. Calvert St., Suite 405, Baltimore, MD 21202; phone: (301) 659-0232.

Braille Materials

1. The Diabetics Division of NFB introduces its **Resource List of Aids and Appliances** in braille. Cost: $2.00. Make checks payable to the National Federation of the Blind and order from: Martha LaQue, 284 Caddo St., San Antonio, TX 78211; phone: (512) 924-7606 or (512) 927-3882.

Cassettes

1. Diabetes In the News (D.I.T.N.): If you are a blind person, check with your regional library for the blind and physically handicapped to see if this tape is offered. If not, you may order D.I.T.N. on loan at no charge from: South Dakota State Library for the Blind and Physically Handicapped, 800 N. Illinois, Pierre, SD 57501; phone: (605) 773-3514.

2. A Professional Approach — Nutritional Care for Diabetes Mellitus: This book explains the goals of nutrition therapy. It is published by the Kentucky Diabetes Foundation, Inc., and we, the Diabetics Division of NFB say "Thank you for allowing us to transcribe, this book onto tape." Cost: $1.00. Order from our Resource Librarian: Cheryl McCaslin, 3115 Crestview, Apt. 107, Dallas, TX 75235; phone: (214) 528-4818.

3. Cassette explaining Potassium and Sodium levels in different foods, Cost: $1.50. Order from Guild for the Blind, 180 N. Michigan Ave., Suite 1720, Chicago, IL 60601.

3. Resource List of Aids and Appliances: instruments that will enable the blind diabetic to self-manage his or her disease. Tape cost: $1.00. For a print copy send self-addressed stamped envelope. Order from: Martha LaQue, Our Aids and Appliances Chairperson, 284 Caddo St., San Antonio, TX 78211; phone: (512) 924-7606 or (512) 927-3882.

Print

1. Free Cook booklet: Jim "Catfish" Hunter was diagnosed as a diabetic in 1977 when he was pitching for the New York Yankees. He is the author of a booklet with 10 recipes which is produced by the Up-John Company. To receive a free copy, write to: "Cooking with 'Catfish' Hunter," P.O. Box 307-C, Coventry, CT 06238.

2. Exchange list in large print: This is the new ADA exchange list for diabetics. Cost $3.50. Contact your local affiliate of the ADA or telephone toll-free: (800) 232-3472.

3. The Diabetic's Book by June Biermann and Barbara Toohey: This book claims to answer all of your questions about diabetes. In our review of this book we found it to be comprehensive. Many questions are answered. Cost: $9.95 plus $2.50 shipping and handling. Order from: Sugar Free Center, Inc., P.O. Box 114, Van Nuys, CA 91408, telephone toll-free: (800) 972-2323 in California. (800) 336-1222.

4. The Physican Within by Cathy Feste: This book is about self-motivation and claims to help people in following either a pattern of healthy living or their specific medical regimen. Cost $8.95 plus $1.50 shipping and handling. Item no. BID19. Order from the Diabetes Center Pharmacy., P.O. Box 739, Minneapolis, MN 55391; phone toll-free: (800) 848-2793.

5. Diabetes: The facts that let you regain control of your life by physicians Charles Kilo and Joseph R. Williamson: The authors of this book believe that diabetes can be controlled and that its complications can be prevented or long delayed in most diabetics. Published by John Wiley and Sons, Inc.; Cost: $9.95.

Tidbits And Humor

(Editor's Note: The jokes used in this issue of *Voice of the Diabetic* have been "stolen" from *The Bell, The Clapper, and The Cord: Wit and Witticism,* which was published by the National Federation of the Blind as a compilation of the jokes included in the "Presidential Releases" of Dr. Kenneth Jernigan, former President of the National Federation of the Blind.)

Gripe Box

Valorie Clare Powell, from Salt Lake City, UT, wrote to suggest that our newsletter include a gripe box. Readers could send in their gripes about diabetes — its complications, management, etc. — and other readers could submit their comments and/or solutions. Please send your unsolved gripes or solutions to *Voice of the Diabetic,* 811 Cherry St., Suite 306, Columbia, MO 65201. Submissions may be anonymous.

A Little Mixed Up

Editor's Note: This poem appears in the *Insight* newsletter, April 1987 issue, and is published by the NFB of South Dakota.)

Just a line to say I'm living,
That I'm not among the dead,
Tho' I'm getting more forgetful
And more mixed up in my head.

For sometimes I can't remember
When I'm standing at the stair
If I'm going up for something
Or I've just come down from there.

And before the "frig" so often
My poor mind is filled with doubt.
Have I put the food away,
Or have I come to take some out?

Then, those times when it is dark out,
With my night cap on my head,
I don't know if I'm retiring
Or just getting out of bed

So if it's my turn to write you
There's no need in getting sore
I may think that I have written
And don't want to be a bore.

Just remember, "I do love you,"
And wish that you were here.
There's the mailman at the corner,
I must say "Goodbye, my dear."

P.S. There I stood beside the mailbox
With a face so very red —
I should have mailed your letter
But I opened it instead.

— *Anonymous*

Free Tape and Record Players

Regional libraries for the blind and physically handicapped provide cassette and disc record players free of charge to the blind. This equipment offers the blind reading material that otherwise would be inaccessible to them. To receive the equipment, contact your regional library for the blind and physically handicapped. For assistance in locating your library, contact your local public library or telephone the National Library Service for the Blind (part of the Library of Congress).Their toll-free number is: 1-800-424-8567. If you are calling from Washington D.C., call (202) 287-5100.

Did you hear about the oculist who fell into the lens grinder and made a spectacle out of himself?

Braille Calendars

The American Brotherhood for the Blind is offering free-of-charge an attractive 1988 calendar in Braille. Just write to the American Brotherhood for the Blind, 1800 Johnson St., Baltimore, MD 21230.

Pancreas Committee

Our new Pancreas Committee chairperson is Linda Bingham, 7146 River Rd., Cincinnatti, OH 45233; phone: (513) 941-1193.

Five years ago Linda received a simultaneous kidney and pancreas transplant, and to-date all three (Linda, kidney and pancreas) are together and working perfectly. Linda welcomes your questions about and interest in transplantation.

Information Please

If you have questions concerning different aspects of diabetes, a good person to contact is a resource librarian. The Diabetics Division of the National Federation of the Blind has its own resource librarian — Cheryl McCaslin.

Our resource library is increasing rapidly thanks to the articles that NFB members send to Cheryl. She has information available on: diabetes (in general), aids and appliances for diabetes, diabetes and its effects on men and/or women, diet and weight control, retinopathy, neuropathy, insulin, and transplants (both kidney and pancreas).

Cheryl encourages NFB members to utilize this valuable source of information about diabetes and to continue sending articles concerning diabetes and/or diabetics to our resource library. Send your questions, articles, comments or requests to Cheryl McCaslin, 3115 Crestview, Apt. 107, Dallas, TX 75235, or call Cheryl at (214) 528-4818.

The surgeon said to the stubborn patient who wouldn't buy hospital insurance: Alright, suture self.

Do You Know?

The National Federation of the Blind is not an organization speaking for the blind. We are the blind speaking for ourselves.

In Memory Of

Jeanne Elizabeth Calusine died on Nov. 19, 1987, at the age of 39. She was a charter member of the Connecticut Chapter of the National Federation of the Blind. Jeanne was the person who gave our newsletter its name, *Voice of the Diabetic.* She was an active Federationist and did everything possible to help the National Federation of the Blind.

Her mother, Theresa Calusine, asked that everyone send "prayers" for Jeanne. The passing of a friend can be difficult and we send our love and prayers to Jeanne's family.

(Continued on page 28.)

PERMISSION TO COPY

We grant anyone permission to copy any portion of our newsletter. We ask only that you let whomever receives a copy know where it comes from and how to contact us.

Subscription/Donation/Membership Form

Although the $2.00 annual membership fee of the Diabetics Division of the National Federation of the Blind (NFB) entitles you to a year's subscription to Voice of the Diabetic, production cost per annual subscription of the Voice is about $6.00. For this reason, we must charge all non-members, health professionals, and institutions $6.00 for an annual subscription. Of course, all donations are accepted and very much appreciated.

If you wish to become a member of the Diabetics Division of NFB, receive a copy of Voice of the Diabetic, or make a donation to the Diabetics Division of NFB, please check the appropriate box or boxes below:

☐ I would like to become a member of the Diabetics Division of the NFB and receive *Voice of the Diabetic:*
☐ in print ☐ on cassette tape* ☐ both in print and on cassette tape* ($2.00)
*cassette tapes are provided to the blind on-loan at no extra cost.

☐ I am a non-member or health professional who would like to receive *Voice of the Diabetic.* ($6.00)
(Also institutional rate)

☐ I would like to make a tax-deductible contribution of $_____ to the Diabetics Division of the NFB.

Please print clearly

Name _____

Address _____

City _____ State _____ Zip _____

Telephone Number (_____) _____

Send this form or a facsimile along with your check to our treasurer:

Carol Anderson, 23 Lake Shore Drive South, Randolph, NJ, 07869.

Please make all checks payable to the NATIONAL FEDERATION OF THE BLIND.

Tidbits and Humor

(From page 27.)

Cut Down On Salt

Thoroughly mix:
3 tsp. dry mustard
3 tsp. onion powder
3 tsp. paprika
1 tsp. garlic powder
1/2 tsp. pepper
1/4 tsp. ground basil

Store in salt shaker and use in place of salt. Can be used on roasts or other cooking, also.

— (Anonymous)

Newsletter Tape

For a cassette tape of this issue of the *Voice*, send your check or money order for $1.00 to Ed Bryant, 811 Cherry St., Suite 306, Columbia, MO 65201.

Extra Voices

We sell newsletters in groups of five for $3.00. Please make your check or money order payable to The National Federation of the Blind. Send your order to: Voice of the Diabetic, 811 Cherry St., Suite 306, Columbia, MO 65201; phone: (314) 875-8911.

Dan Hicks of Florida says that an auctioneer looks forbidding.

Tandem Bicycle Tour

Want to shake off the winter blahs? Let's go on a tandem bicycle tour of the beautiful country of Holland organized by International Bike Tours for visually impaired and sighted people. Enjoy the people, fields of tulips, and good food on this marvelous eight-day tour from May 14-22. Land cost for the tour is $900.

This includes accommodations in good hotels, daily breakfasts, three dinners, use of tandems, sight seeing, our famous T-shirt, tips and taxes. Air fare varies upon the city of departure. I.B.T. will make all arrangements. Reservations for this tour go quickly, so get in touch with Jodi Myers, (419) 625-3758, 637 Cedar Point Rd., Sandusky, OH 44870, as soon as possible.

Hotline Numbers

Following are hotline numbers so you can obtain free medical information and keep up-to-date on the latest research:

1. Blindness and Physically Handicapped Available Programs: The National Library Service for the Blind (part of the Library of Congress). Phone: (800) 424-8567 or in Washington, D.C., (202) 287-5100.

2. Diabetes: The American Diabetes Assocation (ADA), (800) 232-3472 or in Virginia, (703) 549-1500.

3. Diabetes: Juvenile Diabetes Foundation. (800) 223-1138 or in New York, (212) 889-7575.

4. Heart Disease: Heartline. Sponsored by the Association of Heart Patients. (800) 241-6993.

5. Kidney Disease: The American Kidney Fund. (800) 638-8299. In Washington, D.C., (301) 986-1444. In Maryland (800) 492-8361.

6. Surgery: Second Opinion Hotline. Sponsored by the U.S. Government Department of Health and Human Services. (800) 638-6833. In Maryland, (800) 192-6603.

7. Drugs: Drug Interaction, Drug Side Effects. Food and Drug Administration (FDA). Center for Drugs and Biologics. Office of Consumer and Professional Affairs, Rockville, Md., (301) 443-1016.

Medicine by Mail at Low Cost

Mr. Marc Maurer, President of the National Federation of the Blind, recently announced that the NFB and HSN Pharmaceuticals have worked out a cooperative arrangement so that members of the NFB can receive prescription medication and other over-the-counter medical supplies through the mail. The prescription labels will be marked in Braille and print and pertinent data such as other substances which should not be taken with it will be provided.

HSN Pharmaceuticals will deliver prescription drugs to your front door plus make a substantial contribution to NFB when you use group number **10002** when placing an order. For more information, call HSN Pharmaceuticals toll-free (800) 289-7979.

You will be enlightened with more detailed information in the next issue of *The Voice*.

Q: Do you know how to tell a male chromosome from a female chromsome?
A: You take down its jeans.

Make Your Voice Heard

As editor of the *Voice*, I would like to hear about any foul-ups or goofs, as well as your recommendations and criticisms. Please send them, along with any recipes or articles you might want to share with our readers, to the *Voice of the Diabetic*.